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ABSTRACT

The record of the 1985 hearing addresses policy issues concerning families of disabled children. Statements are presented from parents of severely disabled children, educators, researchers, agency personnel, and disabled consumers. Topics addressed include sources of family stress, need for financial and respite services, the effects on other family members, the importance of vocational training, the degree of physician involvement, and the extent of families' health care access and use. Appended papers and supplemental materials, which comprise most of the document, consider such topics as women's labor force activity, marital dissolution, support for families of autistic and autistic-like children, and services for infants with special needs. (CL)

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FAMILIES WITH DISABLED CHILDREN: ISSUES FOR THE 1980'S

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HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

HEARING HELD IN ANAHEIM, CA
APRIL 19, 1985

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FAMILIES WITH DISABLED CHILDREN: ISSUES FOR THE 80'S

FRIDAY, APRIL 19, 1985

House of Representatives,
Select Committee on Children, Youth, and Families,
Washington, DC.

The committee met, pursuant to notice, at 10:35 a.m. in the Malibu Room, Anaheim Hilton and Towers Hotel, 777 Convention Way, Anaheim, CA, Hon. George Miller presiding.

Members present: Representatives Miller, Lehman, Monson, Vucanovich, and Evans.

Staff present: Ann Rosewater, deputy staff director; Jill Kagan, research assistant; Christopher Reynolds, professional staff.

Chairman **Miller**. We will now call the first panel. Beverly Bertaina, from Sebastopol, CA; Mary K. Short, from Fountain Valley, CA; Lisbeth J. Vincent, associate professor for the Department of Studies in Behaviorial Disabilities at the University of Wisconsin, Madison; Ann K. Turnbull, the acting associate director, Bureau of Child Research, University of Kansas, Lawrence, KS; and John A. Butler, who is the principal investigator of the cooperative study of children with special needs, the Children's Hospital Medical Center, Boston, MA.

Welcome to the committee. We will recognize you in the order in which you appear in the witness list. We are all going to have to speak up so that the people in the back of the room will be able to benefit from your testimony.

Opening Statement of Congressman George Miller, a Representative in Congress From the State of California, and Chairman, Select Committee on Children, Youth, and Families

Welcome to the Select Committee on Children, Youth and Families.

Today we will continue to explore, as we have for two years, the needs of our families and the children who live in them. Our members, of both parties, understand and appreciate the importance of building an information base to allow for intelligent policy making, especially in light of the social and economic changes confronting us.

This hearing—"Families with Disabled Children: Issues for the 80's"—continues our series looking at families living in special or unusual circumstances.

As always, we will try to learn how to prevent the destablilizing stresses these families may suffer and how to ensure that chronically ill or disabled children have equal educational and employment opportunities. We will look at ways to make the best use of public and private resources so that these families and children receive the supports they need to enjoy independence and stability.

I know today's hearing will be an important one. We will learn directly from families with disabled children how they deal with child care, health care, with education and with other family needs. We will hear from innovative service providers. And, as always, we will gather the best available research data. I think it will become evident, however, that our government still does not commit adequate resources to learning about those who are disabled or their needs. And there is little dispute that the resources committed to providing necessary services are sorely inadequate.

Perhaps our work here today will help bridge some of the gaps. I think all members of Congress want to move forward, not backwards. I think they are more sensitive than some others in Washington, who have recently made some unfortunate and unfair public remarks on the subject we will be talking about today.

I look forward very much to your testimony.

FAMILIES WITH DISABLED CHILDREN—FACT SHEET [*]

HOW MANY CHRONICALLY ILL AND DISABLED CHILDREN ARE THERE? [**]

A widely accepted estimate of the prevalence of handicaps in the population under age 21 is 11.4% (9.5 to 10 million children). (Kakalik, 1973)

Over two million children, double the number since 1958–61, suffer some degree of limitation of their activities because of their health or disability. (Newacheck, Budetti, and McManus, 1984)

Just over one million children (1.5% of the childhood population) are limited in their ability to attend school. (Newacheck, Budetti, and McManus, 1984)

Anothe 9 million have less severe chronic illnesses. (Vanderbilt Institute for Public Policy Studies, 1983)

STRESSES THAT CHALLENGE FAMILY STABILITY

Families with a disabled child are about twice as likely to experience divorce or separation. (Breslau, unpublished, 1985; Bristol, 1984)

Nearly 20% of children with cerebral palsy seen over a twelve month period at one Chicago care center had been abused. (Diamond and Jaudes, 1983)

In 1980, respite care was the need most frequently identified by state social services for families with developmentally disabled children. (Cohen and Warren, 1985)

PREVENTION SAVES MONEY AND KEEPS FAMILIES TOGETHER

In-home care for a severely disabled child costs $7000 to $8000 per year, compared to $38,000 to $40,000 annually for institutionalizing that child. (Disability Rights Education and Defense Fund, 1984; Vincent 1985)

If intervention for handicapped infants is delayed until age six, education costs to age 18 are estimated at $53,350. If intervention services begin at birth, education costs are estimated at $37,272. Total savings: $16,078. (U.S. Dept of Education, 1985)

For every $1 invested in high quality preschool programming, there is a $3 reduction in public special education costs. (Schweinhart and Weikert, 1980)

A Colorado study which analyzed the cost-effectiveness of a quality preschool program found a cost-savings of $2000 per pupil in averted special education services. (Weiss, 1981)

HANDICAPPED CHILDREN: IN OR OUT OF SCHOOL?

Although as many as 10 million children are estimated to have handicaps and may need special education services, in 1983–84, 4,341,399 handicapped children, ages 3-21, were served under the Education of the Handicapped Act. (U.S. Dept. of Education, 1985)

Almost half the children served were identified as 'learning disabled'; and the increase in the learning disability category (from 797,213 in school year 1976–77 to 1,811,489 in 1983–84) accounted for the greatest proportion of the total increase in children served since 1976–77. (U.S. Dept. of Education, 1985)

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[*] A complete list of references is available upon request

[**] Who is defined as handicapped or disabled may include those within a broad range: those with mild mental retardation or learning disabilities to those with hearing impairment, visual impairments, severe physical disabilities, multiple-handicaps or chronic illness. Depending on the definitions used, estimates of the percentage of children with disabilities may range from 4% to 24% of the childhood population. (The Children's Policy Research Project, 1980) Estimates of the number of handicapped children are highly unsatisfactory because many children are incorrectly classified as handicapped, others posses undetected disabilities. (Gleidman and Roth, 1980).

It is estimated that 1 million preschool-age handicapped children need special education services. However, in 1983-84 only 243,087 3-5 year olds received service under P.L. 94-142, barely an increase from the 232,000 children served in 1975. (U.S. Dept. of Education, 1985; Vincent, 1985)

FINDING A JOB: FEW OPPORTUNITIES FOR DISABLED YOUTH

Many disabled students graduate from the regular educational curriculum. Another 250,000 to 300,000 disabled students leave or graduate from special education each year. And, in Colorado, fifty percent of special education graduates participated in post-secondary education at some time in the 4 to 7 years following graduation. (U.S. Dept. of Education, 1984 and 1985)

Nevertheless, between 50%-80% of working-age disabled adults (6 to 10 million persons) are jobless. Those for whom publicly supported day and vocational services are available often experience low wages, slow movement toward employment, and segregation from their non-disabled peers. (U.S. Dept. of Education, 1984)

Between 50%-80% of former special education students are employed. However, among more severely handicapped students in the state of Washington, only 21% were employed. Even for more widely handicapped youth, almost all jobs were in part-time, entry-level service positions. A Colorado study found that special education graduates were earning at or below minimum wage. (U.S. Dept of Education citing three studies, 1985)

MEETING THE COST OF HEALTH CARE

Forty percent of all disabled children in poverty are ineligible for Medicaid. (Vanderbilt Institute for Public Policy Studies, 1983)

Estimated average expenditures for health services for chronically ill or disabled children may be 10 times as high as for non-disabled children ($3200 compared to $300 per year in 1978 dollars). (Breslau, 1984)

While 68% of all children receive health benefits under group plans, many costs faced by families with chornically ill or disabled children are not covered. Many families are excluded from participation by private insurers because of refusal to cover pre-existing conditions (Vanderbilt Institute for Public Studies, 1983)

In a random sample of children with disabilities in five of the largest school systems, a significant percentage had no regular source of health care, no regular physician, or no public or private health insurance. (Butler, 1984)

Chairman **Miller**. Beverly, if you would like to proceed.

STATEMENT OF BEVERLY BERTAINA, PARENT, SEBASTOPOL, CA

Ms. **Bertaina**. My name is Beverly Bertaina.

Chairman **Miller**. You are going to have to speak up because the microphone is for the recorder——

Ms. **Bertaina**. Oh, I see.

Chairman **Miller**. And unfortunately, not for the room.

Ms. **Bertaina**. OK.

My name is Beverly Bertaina, and I am Adam's mom. (Makes sign with hand.) I got this nickname when we sat in at the HEW building in 1977. Adam is 12 years old. He has severe disabilities, including profound retardation, cerebral palsy, and seizure disorder. I hate always having to start out this way, but it is necessary in order for the people to understand the magnitude of our situation.

In the United States and in California, parents of children and adults with disabilities are faced with a number of appalling choices in every stage of their child's life and development. I will be discussing the choices we have been making recently, and will be making in the near future.

Do we allow our child to be educated in a second-class segregated school, or do we fight to get them into an integrated program, which, in my situation, ended up an hour across the county from our home?

Special education is the single most important support system available to families with disabled children. Since Public Law 94-142 passed, great progress has been made in providing disabled children with an appropriate educational program. However, the letter and spirit of that statute has been consistently violated in the area of integration. Many students are still placed in expensive, segregated facilities, not because they need to be there, but because the facilities exist, and administrators want them filled.

I understand that Orange County has been attempting to get approval from the State to construct a new segregated facility. Integrated programs cost less, and provide a far better education, but it is very hard to get your kid into an integrated program if they are severely disabled.

It took us 2 years and a fair hearing to get our son out of the development center. We got him into an integrated program, but it is 15 miles and an hour's ride across the county from our home. Transportation costs are tremendous because the schools in our district refuse to provide programs for the severely disabled students who live in their districts. We pay property taxes there, but we cannot get our kids into our own schools.

Regular education students have first priority for space in schools, and if anything is left, special ed students may get it, although they may also get kicked out the next year, if they need the space for somebody else.

Only special ed students are told there is no room or no program, "go somewhere else." Schools do not care how far, how inappropriate, or how segregated "somewhere else" might be.

In the past, parents could depend on the Federal Government to be the final defender of their children's rights, but since President Reagan was elected, the Federal Government has acted more to limit those rights than to expand them.

I wish to thank Congress for refusing to cooperate with the administration in repealing and block granting the funds for Public Law 94-142, and Section 504.

Another choice we have had to make is do we allow our child to use segregated services, or do we battle to get into generic community services. There are no camps. There are a hundred camps in our area in Sonoma County, none of which will accept our kids. So, we have to drive them a 150 miles south to a special segregated camp in Santa Cruz. There is no integrated swimming program at the YMCA, no integrated after school programs, or recreation programs, and there is very little child care.

Parents with children with severe disabilities need child care as much or more than other parents, and they need it for a longer time. We were fortunate in finding an integrated program with a family who has a disabled child and is not afraid to deal with him. But, we are charged a third more than the other parents. The children in the child care center are much younger than Adam, but there is no age appropriate option for anything after school.

Regional center, the regional center system in California, one of their mandates was to deal with this situation, to try to get generic services to include our kids, but they are so under-funded, it has never been done.

Do we ruin ourselves financially or do we place our kids? This is a terrible quandry that many parents face. It is an amazing paradox that institutional care for Adam would cost between $30,000 to $65,000 per year, but the Federal and State Government is willing to spend, for us, only $2,000 to $3,000 a year to help us keep Adam at home.

Adam's medical expenses are very large. We are fortunate that my husband carries very good medical insurance, but many families do not. We had a recent emergency where Adam choked and had to go to the hospital. The ambulance ride and the emergency room treatment alone was almost $1,000; for a family with no insurance, it would have been incredible.

Adam uses very expensive equipment. A $3,000 wheelchair, a walker, an arm support for feeding. Our 7-year-old van with ramps will soon have to be replaced with probably at least a $15,000 van with an electric lift. I know of no help that we can look for from anyone.

Diapers. That does not seem very important, except he is going to be outgrowing Pampers pretty soon, and the cost of diapers will then raise to $8.75 a dozen. He goes through a dozen in 2 days.

A specially-trained sitter costs $6 to $9 an hour. Adam's camp costs $475 for 10 days. When our daughter went to camp, it cost $100. The difference between the $100 and the $475 is not tax deductible. Very few of our expenses are, and if a flat tax is adopted, none of our expenses will be tax deductible.

If we place Adam now, we will be charged at the maximum rate by the State for reimbursement for his care until he is 18. So, we are caught one way or the other.

Do we place Adam outside our home when he is 18 and he is ready, or do we do it now and deprive him of the family life that every 12-year-old is entitled to? He is getting harder and harder for us to deal with at home. We get 20 hours of respite services, but that is not sufficient to help us with diapering, dressing, enemas, bathing, feeding, lifting. We lift him in and out of his chair, in and out of his bed, in and out of his walker, in and out of the bathtub, up and off the floor. It is exhausting.

There is also tremendous pressure from his school, his doctors, his therapists, and from our own sense of responsibility, to try and do everything. For example, it is very important that his educational program be continued at home; in special positioning, he needs to use a special arm support when he is learning to feed himself, in using the communications board, in giving him extra simulation and attention. We are running out of energy.

Our teenage daughter shares a great deal of this with us, but when she goes out on her own next year, it is going to be that much more for my husband and I to deal with.

It is really outrageous that if we place Adam outside our home, he will receive more services than he can get inside our home. In placement, he would get full SSI benefits, further financial assistance from the regional center, full medical and dental care, free diapers delivered to the door, free transportation, free equipment, full attendant care. None of which we can get at home.

Just considering respite, we need 2 to 3 hours of respite daily, plus 20 additional hours monthly for when he is out of school, on holiday, or sick, and 10 days a year, at least, for a consistent sustained break from his care. This may sound like a great deal, until you understand that we have used up a 2 month allotment of respite in order for me to be here today. We will get no respite for the next 2 months.

I work as an independent contractor. When I do not work, I do not get paid. Most of my income goes for child care and for other expenses for Adam. I appreciate that this committee paid my transportation, but I really wish I had thought to ask for child care expenses. That probably should be something that is offered to families when they are testifying.

One of the choices we will be making—at least, I hope, not until he is 18—is do we place him in a State hospital or do we spend years finding or creating a community placement for him? We have always pledged to ourselves and to him that we would never place him in a State hospital. We feel that large institutions can never be a good place to live. I would not live in them. You would not live in them. Adam is not going to live in one either.

Community residences have been shown time and again to be far superior and far more cost-effective. We have watched many of our friends with adult children spend years looking for a good place, to finally find one, then to be placed on a waiting list, or to watch it close after a short time because of insufficient funding. We really dread the time when we will have to start that search.

Cuts in services in funding in the last few years are a serious blow to families with disabled children. State hospital placements are on the rise again in California because families are breaking under the pressure.

We have, for the first time, seriously considered placing our son. We do not want to, but we honestly do not know how long we can keep going.

I would like to say that special education, as well as regular education has recently begun to realize that it is not enough to teach children to be good students, and to function in a school environment. The emphasis is beginning to change to training students, especially those with severe disabilities, to be functioning participants in the full range of activities provided in our society, such as home life, social/recreational activities, and especially meaningful employment.

Marvelous work is being done in Madison, WI, and other places, to begin training severely disabled students from age 12 to live, work and play in their communities. The transition from school to work has been important and a difficult process for young adults with disabilities.

I am encouraged that the Department of Education recognizes this, and has provided leadership under Mrs. Will to deal with transition. I know without this kind of assistance, Adam has little chance of succeeding in his move from school into adulthood and independence. Thank you.

[Prepared statement of Beverly Bertaina follows:]

PREPARED STATEMENT OF BEVERLY BERTAINA

My name is Beverly Bertaina and I'm Adam's Mom. He is 12 years old and has severe disabilities including profound retardation, cerebral palsy and a seizure disorder. Adam does not speak, or walk nor is he toilet-trained. He has almost daily seizures. I say this not so you will feel sorry for him but only so you will realize the magnitude of our situation.

In the United States and in California, parents of children and adults with disabilities are faced with a number of apalling choices at every stage of their lives and development. In the short time we have here I will discuss only those choices we have made recently or will make in the near future.

1. Do we allow our child to be educated in a second-class segregated school where we will never see a non-disabled child or do we fight to get him into an integrated program which is a one-hour bus ride across the county?

Since PL 94-142 (the Education for All Handicapped Children's Act) was passed in 1972, great progress has been made in providing disabled students with an appropriate educational program, however, the letter and the spirit of that statute are consistently violated in the area of integration. Many students are still placed in segregated schools not because they need to be there but because the facilities exist and administrators want to see them filled.

I took us two years and a fair hearing to get Adam into an integrated program but it is 15 miles and a one-hour bus ride away. Transportation costs are tremendous because many school districts refuse to provide a program for their severely disabled students in their local school. Regular education students have 1st priority for space in schools and special education students get what's left, if any and often lose that when the room is needed for something else.

In the past, parents could depend on the federal government to be the final defender of their children's rights, but since President Reagan was elected, the federal government has acted more to destroy those rights. I wish to thank Congress for refusing to cooperate with the administration in destroying PL 94-142 and Section 504.

2. Do we continue to allow our children to use segregated community services or do we battle to get generic services to include our children?

There are no camps (out of the many in our area) which are prepared to accept our son, so we drive him 150 miles south. There are no integrated swimming programs at the YMCA, there are no integrated after-school programs, recreation programs or child-care. Parents of children with severe disabilities need child-care as much or more than other families and usually for a longer time. We were fortunate in finding integrated after school child-care for Adam with a family who has a disabled child and is not afraid to deal with him. But we are charged one-third more than the other parents are charged.

All this segregation is redundant and unnecessary and costs our society a great deal in money and in lost opportunity to experience what disabled children have to offer.

3. Do we ruin ourselves financially or place our child before he is ready?

It is an amazing paradox that institutional care for Adam would cost $35,000 to $65,000 per year but the federal and state government are willing to spend only $2-3,000 per year to help us keep Adam at home.

Adam's medical expenses are very large including two expensive seizure medications taken daily, frequent blood and other tests and visits with at least four different doctors. We are fortunate that my husband's employer provides good medical and dental coverage but many families do not have this. During a recent emergency when Adam choked and stopped breathing, the cost of the ambulance ride and emergency room treatment alone was almost $1,000. It is difficult to find adequate dental and orthodontal care for persons with severe disabilities even if you have insurance. I understand from friends that Medi-care reimbursement is grossly inadequate.

Adam also needs expensive equipment including: $3,000 wheelchair (paid for by Regional Center), $150 walker, $100 arm support for feeding (provided by the school).

A van with ramps (when our seven year old van is replaced, it will cost at least $12,000 plus $3,000 more for an electric lift).

Diapers at $50 per month (when Adam outgrows children's sizes soon, the cost will increase to $150).

Working parents who can find an agency to assist them in purchasing some of this equipment must be very careful because they may be asked to repay the full amount plus interest.

When child-care is available (which is seldom) it is more expensive than usual. In our area, a specially trained sitter receives $6 to $9 per hour. Adam's camp cost $475. Many of these extra expenses are not tax deductible and none will be if a flat tax is adopted.

If we did place Adam before he is 18 years old, we would be charged by the state at the maximum rate of his care.

4. Do we place Adam outside out home at age 18 when it's appropriate or do we place him at age 12 and deny him the family life that every 12 year old is entitled to?

As Adam grows older, he becomes harder to deal with at home and we need more services to help us keep him at home. We are finding that the 20 hours of respite service we are not allotted are totally inadequate in helping us with his daily care—diapering, dressing, enemas, bathing, feeding, lifting, etc. There is also tremendous pressure from his school, doctors, therapists, and from our own sense of responsibility for us to try to "do everything". It is very important that Adams' school program be carried through at home including special positioning, using the arm support in feeding, using the communications board, giving him extra stimulation and attention, etc. But we just don't have the time or the energy to do it all. Our teenage daughter shares a great deal of the work and when she goes out on her own next year, it will be that much more for my husband and I to do.

It is truly outrageous that if we place Adam outside our home, he will receive more services than we can get if we keep him at home. In placement, he would get full SSI benefits, further financial assistance from Regional Center, full medical and dental care, free diapers delivered to the door, free transportation to free community activities, free equipment, full attendant care.

In order for us to keep him at home, we need at least 2–3 hours of respite daily, 20 additional hours monthly for our meetings or when he is sick or on school holidays, and 10 days each year so we can have a sustained break from his care. This may sound like a great deal until you understand that we have used a full two months allotment (40 hours) of respite in order to allow me to attend this hearing and my husband to attend a Regional Center meeting. We will get no more respite for the next two months. I work as an independent contractor and am only paid for the hours I work. When Adam is home sick or on school holiday, I must miss work. Most of my income goes for child care and other expenses for Adam. I appreciate that this committee paid for my transportation but I wish I had thought to ask for child-care expenses.

5. Do we allow our son, as he becomes an adult, to be placed in a state hospital or do we spend months or years finding or creating an appropriate place for him in the community?

Long ago we made a promise to ourselves and to Adam that we would never allow him to go to a state hospital or large institution. It is our opinion that as much money is poured into them, as dedicated as the staff is, as stable as the program is, a large institution can never be adequate, much less a good place to live. Small community residences have been shown time and again to be more cost effective and superior to state hospitals.

We have experienced nothing sadder or more frustrating then watching our friends with disabled children searching for a community residence which is a warm home with a small number of residents (6–8), located in a community with the necessary services, only to be placed on a long waiting list or to see the residence shot down after awhile because of the lack of stable funding. We dread the time when we must start searching.

The federal and state governments have done little and are now doing less to provide sufficient resources to support appropriate community residences and services for adults with disabilities or to monitor the quality of those services.

The cuts in services and funding in the past few years are a serious blow to families with disabled children. State hospital placements are on the rise again because families are breaking under the pressure. We have seriously considered placing Adam outside our home because of the stress. We honestly don't know how much longer we can hold out before the overhelming stress becomes distructive to the rest of the family.

Thank you for listening.

Chairman MILLER. Thank you.

Mary Short. I would also add that Barbara Vucanovich has just joined us. Thank you.

Ms. VUCANOVICH. Thank you, Mr. Chairman.

Ms. BERTAINA. Oh, excuse me. One more thing I forgot. I brought pictures of Adam. I was told one time that people like to know who they are talking about.

Chairman MILLER. Mary?

STATEMENT OF MARY K. SHORT, PARENT, FOUNTAIN VALLEY, CA

Ms. SHORT. Thank you.

My name is Mary Short, and I am a single parent of a 5½-year-old severely handicapped daughter. She has a diagnosis of tuberous sclerosis, an autosomal dominant genetic disorder. Although she chronologically is 5½, developmentally, she has the capabilities of a 14-month-old.

I have been divorced since August 1981. Her father last took her for visitation December 20, 1981. He and I last spoke to one another March 1982. He has been on probation for nonsupport since December 1982, and he will officially end probation December 17, 1985. Even though he is and has been on probation, he is currently $5,050 in arrears in the child support payments.

In July 1984, I placed my daughter in a board and care facility, a small family care home. It is important that you understand that I am very pleased with the home. The care she receives and the fact that she is a part of a "real" family. The progress she has made is truly amazing to me. I am very thankful to the care provider and her family.

The events that occurred from March 1982 until June 1984, a total of 27 months, demonstrate my experience with agencies that generally do not provide supportive services. Child support enforcement. My court order is for $350 a month. The attitude of the Orange County district attorney's office and the probation department is that "this is an unusually high support order."

At the time we divorced, he was bringing home between $3,000 and $3,500 a month. I do not think 10 percent of his take-home pay is too high. If he changed employment since the divorce, and he is no longer making $3,000 a month, it is his responsibility to take me back to court to modify the support order.

Effective child support enforcement is one of the deciding factors in whether or not my daughter is at home with me or in and out of home placements.

Respite day care and babysitting. When my daughter became a client of regional center of Orange County in January or February of 1981, they offered 48 hours a month and a vacation period not to exceed 21 consecutive days of free, in home or out of home, respite to each in-home client.

Effective July 1984, each in-home client is entitled to 24 hours of respite per quarter, noncumulative. By the way, there is an exceptions policy to that rule.

The loss of respite, which I personally have viewed as what other more fortunate single parents call visitation, was a major deciding factor in my decision to place my daughter.

There is no such thing as day care available to my daugther. It does not matter who pays for it or what the cost is, it simply does not exist. I went through two licensed and four unlicensed day care homes, six children and under, and one roommate. All but one told me on a Friday afternoon that they could no longer watch my daughter for whatever reason.

Money was never given to me as a reason. Not a single day care center was available to me. There are two that I am aware of that do take handicapped children. Unfortunately, they both meant 40 miles a day traveling in the wrong direction, which made them also out of the school bus range for pick up and drop off.

Lack of day care was the deciding factor in my decision to place my daughter. I could not continue to disrupt my daughter with constant changes and I refused to lose a third job over day care.

Simply finding a babysitter so that I could go out to a movie, God forbid I was asked on a date, became a major project. The babysitter had to, first, not be afraid of my daughter and, second, either live close enough to me to walk to and from her own home or be able to drive.

Financial aid. Except for giving up and going on welfare, nothing is available to me if my daughter remains in my home. Even welfare is not a solution since there is a rule about having to seek employment when the youngest child reaches school age, and Public Law 94-142 defines school age as age 3, not age 5.

I cannot become a licensed day care provider myself and take other handicapped children into my home because there is some rule about income from care providing not being your sole source of income.

When I am working, I earn too much money to qualify for SSI, they count child support, or to qualify for Medi-Cal's share of cost. The share of cost program had fixed my monthly repay at something like $300 each and every month. California Children Services covered all medical expenses related to seizures up until they were controlled for 6 months. Then, after she was on $75 a month worth of medication to control the seizures, they cut us off cold turkey.

To conclude, with my daughter at home, we received nothing. Now that she is placed out of home, it is costing the system $868 a month, plus Medi-Cal, to maintain her. And, I still bring her home every other weekend.

I consider this place to be temporary. The only solution for myself and my daughter is for me to earn enough money all on my own so that I can hire live-in help. Only with a truly employer-employee relationship will I be able to provide the security and stability that my daughter needs. I hope one day to be able to say, when someone asks me about supportive services that are and are not available, gee, I do not know, I am able to provide them all on my own. I do not keep up with those sorts of things.

But, in the meantime and for the benefit of other parents like myself, there needs to be a solution found for day care, for respite, and for some realistic assistance with medical expenses. For those of us who, for whatever reason, do have our children placed, the system is efficient

The system for in home and out of home handicapped children needs to be equalized. Public Law 94-142 gave that to a certain extent to all of us for education and the same can be done with supportive services.

Thank you for your concern and attention to this issue.

Chairman **Miller**. Thank you.
[Prepared statement of Mary Short follows:]

Prepared Statement of Mary Short, Parent

My name is Mary Short and I am a single parent of a 5½ year old severely handicapped daughter. She has a diagnosis of Tuberous Sclerosis, an autosomal dominant genetic disorder. Although she chronologically is 5½, developmentally she has the capabilities of a 14 month old.

I have been divorced since August 1981. Her father last took her for visitation December 20, 1981 and he and I last spoke to one another March of 1982. He has been on probation for non-support since December 1982 and will officially end probation December 17, 1985. Even though he is and has been on probation, he is currently $5,050.00 in arrears in the child support payments.

In July 1984 I placed my daughter in a board and care facility, a small family care home. It's important that you understand that I am very pleased with the home, the care she receives, and the fact that she is a part of a "real family." The progress she has made is truly amazing to me. I am very thankful to the care provider and her family.

The events that occurred from March 1982 until June 1984, a total of 27 months, demonstrate my experiences with agencies that do and do not provide supportive services.

1. Child Support Enforcement: My Court Order is for $350.00 a month. The attitude of the Orange County D.A.'s office and the Probation Department is that "this is an unusually high support order." At the time we divorced he was bringing home between $3,000.00 and $3,500.00 a month. Ten percent of his take home pay is too high? If he has changed employment since the dissolution and is no longer making $3,000.00 a month, it's his responsibility to take me back to Court to modify the support order.

Effective child support enforcement is one of the deciding factors in whether or not my daughter is at home with me or in an out of home placement.

2. Respite, Day Care and Babysitting: When my daughter became a client of Regional Center of Orange County (RCOC) in January or February of 1981, they offered 48 hours a month and a vacation period not to exceed 21 consecutive days of free, in home or out of home respite to each in home client. Effective July 1984 each in home client is entitled to 24 hours of respite per quarter, non-cumulative. By the way, there is an exceptions policy. The loss of respite, which I personally have viewed as what other more fortunate single parents call "visitation," was a major deciding factor in my decision to place my daughter.

There is no such thing as day care available to my daughter. It doesn't matter who pays or what the cost is. It simply does not exist. I went through two licensed and four unlicensed day care homes (six children or under) and one roommate. All but one told me on a Friday afternoon that they could no longer watch my daughter for whatever reason (money was never given to me as a reason). Not a single day care center was available to me. There are two that I am aware of that do take handicapped children, unfortunately they both meant 40 miles a day of traveling in the wrong direction which made them also, out of the school bus range for pick-up or drop-off.

Lack of day care was the deciding factor in my decision to place my daughter. I could not continue to disrupt my daughter with constant changes and I refused to lose a third job over day care.

Simply finding a babysitter so that I could go out to a movie became a major project. The babysitter had to first, not be afraid of my daughter and secondly, either live close enough to walk to and from home or drive their own car.

3. Financial Aid: Except for giving up and going on welfare, nothing is available to me if my daughter remains in my home. Even welfare isn't a solution since there is a rule about having to seek employment when the youngest child reaches school age and PL 94-142 defines school age as three, not five! I cannot become a licensed care provider myself and take other handicapped children into my home because there is some rule about the income from care providing not being your sole source of income.

When I am working, I earn too much money to qualify for SSI (they count child support) or to qualify for Medi-Cal's share of cost program. The share of cost program had fixed my monthly repay at something like $300.00 each and every month. California Children Services covered all medical expenses related to seizures up until they were controlled for six months. Then, after she was on $75.00 a month worth of medication to control the seizures, they cut us off cold turkey.

To conclude, with my daughter at home, we received nothing. Now that she is placed out of my home, it is costing the system $868.00 a month, plus Medi-Cal, to maintain her. And, I still bring her home every other weekend.

I consider this placement to be temporary. The only solution for myself and my daughter is for me to earn enough money all on my own so that I can hire live-in help. Only with a truly "employer-employee" relationship will I be able to provide the security and stability that my daughter needs. I hope one day to be able to say, when someone asks me about supportive services that are or are not available, "Gee, I don't know."

But in the meantime and for the benefit of other parents like myself, there needs to be a solution found for day care, for respite, and for some realistic assistance with medical expenses. For those of us who for whatever reason, do have our children placed, the system is beautifully efficient. The systems for in home and out of home handicapped children need to be equalized. PL 94-142 gave that to us all for education and the same can be done with supportive services.

Thank you for your concern and attention to this issue.

Chairman. MILLER. Ms. Vincent.

STATEMENT OF LISBETH J. VINCENT, ASSOCIATE PROFESSOR, DEPARTMENT OF STUDIES IN BEHAVIORAL DISABILITIES, UNIVERSITY OF WISCONSIN, MADISON

Ms. VINCENT. I thank the committee for the opportunity to appear today. I am Lisbeth Vincent. I am an associate professor in the department of studies in behavioral disabilities at the University of Wisconsin.

I spent the past 15 years working with families and their very young disabled children, children under 6 years of age. I would like to point out that there are approximately 60 million Americans who have a family member who is disabled. We are talking about a large portion of the population when we talk about what are the issues that face families with people with disabilities today.

I am sure that many of you in this room have a cousin, a parent, a brother, a sister, an aunt or uncle, who is disabled and you have in your own experience seen the difficulties that families face.

I hope I can represent those families today as well as the families that I have had the very unique pleasure to learn from in my own professional experience. I am going to focus my remarks on families of the youngest children with disabilities, families of children under 5 years of age.

Imagine being told by your pediatrician that your 18-month-old daughter is slow in language development. She is not talking the way other children are. She is not following directions the way other children are. Imagine that you thought that might be the case, and that you have been worried and then imagine being told there are no services available until your daughter is 3 years of age.

Imagine being the parent of a 6-year-old who has been labelled autistic and severely retarded, that you have worked within your family structure to maintain this child in your home, you have bought babysitting, you have paid double tuition at day care so your child can be in the facility. Imagine having tried six programs to toilet train your child, using the best that the experts could come up with, and not being able to toilet train your child.

And, imagine finding you are pregnant and then, in 9 months, you will have another baby in diapers, and then imagine that in order to get your child toilet trained, somebody says to you, we have a program, you will have to wait 6 months, and you will have to send your child 200 miles from your home, place them in an institutional setting, for 3 to 6 months, where you will not be able to have contact with your son who you have been maintaining at home.

Imagine that you are a parent of a child who was born at 26 weeks gestation, who spent the first 10 months of their life in the hospital, who is on apnea monitors because of their heart stopping, who went through all kinds of respiratory problems, and you made it.

And, imagine bringing that child home, being labelled hearing impaired, mentally retarded, cerebral palsy, and imagine hearing a year after you have had this child home that the best thing for you to do, the only way that our community can provide you service, and meet the needs of your son, is to place him in a State institution for the mentally retarded.

Imagine that you are the average American family who is undergoing the stress that Representative Miller talked about this morning, of divorce, of lowered income, of lack of extended family. Families of disabled children face all of those stresses, as these two mothers so nicely told us, and imagine the stresses I just told you being added on to your family and not just the stress of making it day to day.

These families are all families that I have worked with in the last 6 months. These are not families from 10 years ago, these are not families in the 1950's, these are families in 1985, and their experience is that while they are under the stress of the regular typical family out there, they have at least three kinds of additional stress that are placed on them because of the way we deliver and do not deliver services in our communities.

The first stress placed on them, is that it is not desirable in our society to be handicapped. I do not know any parents who have wanted their children to be labelled handicapped. I have not worked with any families that were delighted at that pronouncement, but I have worked with a large number of families who have adapted to that pronouncement and have learned to cherish their children for what they bring to the family. They have learned to cherish the uniqueness of their children. They have learned to learn from their children.

But, the stress is that they are in a state of shock and then we place a second stress. Their child is under 5 years of age and in half the States in the United States, we do not provide public early intervention. So, now, we have placed an additional stress on a family, a family that is often overburdened with single parenthood, lack of education, we tell them it is your responsibility to go find service, to scramble, to fight, to push, to holler, and all too often the families do that, and then they quit because they are not respond to and they cannot make a difference.

The third stress is for many of the children that are labelled handicapped under 3 years of age, their disabilities are severe. Their problems are multiple, and, in most cases, as Mary so aptly pointed out, as a society, we have chosen that we will spend $40,000 to a $110,000 a year on an institution, and we will spend $2,000 to $3,000 on maintaining the child at home.

We need to make a commitment to change these types of stresses that families of young disabled children face. We passed 94-142 and through it, we have made a major difference in the life space of the families of disabled children between 5 and 18 years of age.

The reality of 94-142 is that it has had limited impact at all for families of children between birth and 5 years of age. Because of the permissive nature of the preschool mandate, some States have lowered their State mandate, nine of them, so that children under 5 will be served. At the same time, eight States in this country have raised their mandates, so that they will not be responsible for serving preschool age kids.

So, we are in a situation where, as professionals, more than ever, we are capable of finding children early. We can screen, we can assess them, we can diagnose. Families are referring to us. We know the children are there. We are keeping kids alive, and then we are putting the family in 5 years of crisis. Five years of not being able to find integrated services. Five years of not being able to find therapeutic services. Five years of not being able to find family support services.

I would like to advocate that what we need to do is not spend more money. I think all too often we look at spending more money as the way of solving our problems. I am firmly convinced that we are spending a great deal of money in the area of the handicapped now, and that we need to look at where we spend it, and who we give it to.

Rather than placing it in institutional based programs, we need to look to provide families the same level of support for maintaining their child at home that we are willing to spend as a society for them placing their child outside the home.

I am committed, and I know the families here are, to reversing the trend, to enabling families to really use the strengths and the unique resources that they bring. Families with disabled children are under stress. Families with disabled children are usually not falling apart.

They are capable and competent people. They have a lot of good ideas about how to solve their problems. As these two moms demonstrated, they know what they need from us as a profession, from us as a government, from us as a society in order to meet their needs.

I hope that what we will be able to do in the next decade, the second decade after 94-142, is to turn it around and enable these families to cherish their children and cherish them at home, in their churches, in their communities, in their neighborhoods, and in their schools.

We thank you very much.

Chairman MILLER. Thank you very much for your testimony.

[Prepared statement of Dr. Lisbeth Vincent follows:]

PREPARED STATEMENT OF LISBETH J. VINCENT, PH.D., DEPARTMENT OF STUDIES IN BEHAVIORAL DISABILITIES, UNIVERSITY OF WISCONSIN-MADISON, MADISON, WI

Thank you for the opportunity to appear before you to discuss issues facing families with disabled children. I am an Associate Professor in the Department of Studies in Behavioral Disabilities at the University of Wisconsin-Madison. I have worked with families of disabled children for the past fifteen years. These family members may number as many as 60 million Americans. These families are first of all families—families facing the same stresses as all American families.

The American family is under considerable stress today and is dramatically different than when I began my work in this field 15 years ago. The nuclear family has, and continues to, disappear. The "Ozzie and Harriet," "Leave It to Beaver," and "Archie Bunker" families with two parents and several children living in a home that they own is simply not a reality for many American children. The notion that mothers remain at home while their children grow up is not true for the majority of children, even preschool age children. The idea that children are listened to and disciplined consistently by sending them to their room or removing privileges is countered by a dramatic increase in child abuse.

What does the American Family of the 1980's really look like? Data available from the 1980 national census and from state level studies paints a picture of families in transition. Only seven percent of families are composed of two parents with father working and mother at home with their children. Ten percent of the people in the U.S. speak a language other than English in their homes. In the U.S. there are 6.6 million one-parent families. That means that 20 percent of families with children are headed by a single parent. In 90 percent of these cases that parent is a woman. Among Black families, 57% of families with children are headed by one parent. In the past twenty years the number of children born to unmarried mothers tripled. In 1980, 17.1% of all births were to unmarried women. Fifteen percent of all births are to teenage mothers. Approximately 40% of the teenage women in this country will become pregnant at least once during their teens. Fifty-three percent will abort the fetus. Of those who carry the baby to term, ninety-six percent will keep the child. Many will never finish their own schooling. Sixty-seven percent of the children born in America today will be raised for a part of their life by a single parent.

This large increase in single parent families (double since 1970) is paralleled by an increase in the number of children being raised in poverty. In Wisconsin, 60% of the female-headed households with children below age 6 live below the poverty line. Approximately 70% of these mothers are single, separated, or divorced. Of the women who are eligible for child support payments less than half receive the amount ordered and one quarter receive nothing at all. In Wisconsin alone, a recent investigation showed that fathers were 100 million dollars in arrears on child support payments.

In 1980, 75% of the single mothers in Wisconsin lived on welfare. The median income of female-headed households in Wisconsin was $10,408. This figure represents half of the income of two parent families where the wife does not work and only one third of the income of two working parent households. women and children are the new poor in the United States. They make up the majority of 13 percent of Americans who live below the poverty level.

Where children are in two parent households, more than fifty percent spend time daily in daycare or with a babysitter before they are six years of age. By 1990, predictions are that 75% of the children in this country under six years of age will be receiving nonparent care.

Not only is there a significant increase in the poverty and out-of-home care that children face, there is also a significant increase in abuse and neglect. Estimates for child abuse in the Midwest during the late 1970's generally predicted that 20 percent of the children were in abusive/neglectful living environments. Some authorities say this figure is low given the increase in unemployment during the early 1980's. Several counties in Southern Wisconsin reported a 100% increase in the incidence of reported child abuse just between 1981 and 1982. In Dane County, reports of abuse and neglect increased 23 percent in the last year. One child characteristic has been correlated with an increased risk of being abused, i.e., behavior problems and developmental delay.

The past ten years have also seen increased concern with the level of drug and alcohol use in our country. Employers estimate vast amounts of lost time, money and productivity due to alcohol abuse. National estimates are that one in ten adults has trouble controlling the alcohol they consume. National estimates are showing an increase in number of teenagers and preteenagers with drinking problems.

The educational implications of poverty, family constellation, out of home care and child abuse and neglect are each significant in and of themselves. Some families are facing not only the stresses outlined but also are coping with a young handicapped child requiring exceptional educational services. Families with handicapped children look much like families of typical children. For example, a recent survey of the records of 200 families with children enrolled in the early childhood/special education program of Madison Metropolitan School District, Madison, Wisconsin revealed that: 50% of the families received Aid to Families of Dependent Children, 44% of the families included unemployed adults, 47% of the families were headed by a single parent, 14% of the children were suspected victims of abuse, 14% of the families received counseling, 26% of the families were involved with more than three community agencies other than the public schools, 31% of the families were highly mobile, 13% of the families had problems with alcohol and drug abuse.

In addition, information gathered from the staff who work directly with parents revealed that approximately 10 percent of the parents had received special education or in-patient therapy services themselves. Also, an increasing number of children are receiving psychiatric care, including medication, before five years of age.

These statistics parallel the statistics presented earlier on American families in general. Having a handicapped child can be yet another stress added to an already highly stressed family. Family priorities differ; in some, obtaining food, clothing, and shelter are primary. The handicapped child is secondary and not a major focus of the family. The issue is not whether the parent "accepts" the child's handicap, but how much time, energy, and resources they have available to devote to this problem. This is particularly true if the handicap is not a visible or severe one. An example of this is a child with a speech and language delay but normal motor and social skills. The language delay is probably a mild problem compared to the many other difficulties the family faces. The existing models for parent involvement in early childhood/special education are based on the handicapped child being of central importance. In a sense, they are based on the family having its primary care needs met, so that it can focus on other problems. Clearly, for a proportion of families this is not the case. These families have an increased risk of child abuse and/or placement of the child outside of the biological family.

If the family is fortunate (only 25%-35% are), they will be residing in a city, village or town that provides the full range of early intervention services necessary to meet their child's developmental needs. Since the passage of P.L. 94-142, services for handicapped children under five years of age and their families have shown very limited growth. In 1975, 232,000 preschool-age handicapped children were receiving public education based services. National estimates are that one million preschool-age handicapped children need special education services. The permissive nature of the preschool mandate contained in P.L. 94-142 has not spurred state and local educational agencies to dramatically increase their services to their young children. Since the passage of P.L. 94-142, nine states have passed mandatory education legislation which lowers the age of educational service to less than five years of age. Eight states have, however, passed mandatory education legislation which raises the age of educational service to five years of age. Thus, families with a young disabled child face not only the stress of family change and the fact of their child's diagnosis as handicapped, but also difficulty in obtaining quality educational and therapeutic intervention services. These stresses, added on to the already stressed family, limits the handicapped child's opportunity for full developmental growth and ultimately his/her contribution to society.

A major issue facing families of disabled young children in the '80s is where their children will be educated. The best solution to this problem rests in mandating that state and local educational agencies assume responsibility for the handicapped child's educational program from the point the child is diagnosed. For some children this means the moment of birth; for others it is during the preschool years. Without a federal mandate, states and local educational agencies will continue to be reluctant to enter the arena of early intervention. Such a mandate would benefit the community, in that it reduces the number of children who are placed in out of home care, e.g., institutions and foster care. Out of home care is more costly than in-home care with appropriate services.

A second major issue facing families of disabled young children is how will they be involved in their child's educational program. Despite the stresses that families are facing, they do wish to be involved and maintain a leadership role with their children's future. Families are capable of generating solutions to the problems they face. The educational, medical, social service, and other support systems need to develop strategies for more active decision-making by family members. Such strategies do not mean that agencies take on the role of solving problems. Rather a family systems perspective needs to be adopted.

Basically, a family systems perspective maintains that each family has available resources it can use to meet its needs. These resources are of both an informal and formal nature. The informal network includes self, spouse, extended family, friends, and coworkers. The formal network includes doctors, educators, social service agencies, etc. In Madison, through a survey of 30 parents of young typical children and 30 parents of young handicapped children, we discovered that the parents developed similar resource networks. Basically, 75% of the resources they identified were from their informal network. The most frequently cited resource was "my own belief in myself and my own motivation." The order from most to least used resources named by the persons was self, spouse, extended family, friend, doctor, educator and co-worker. In a study of 24 families whose children under six years of age were just labeled handicapped, we found a similar order of resources within the informal network of friends and relatives. We also asked that the parents select resources from a list of professionals. Selected first was the pediatrician. The second most frequent selections were teacher, clergy, and ENT specialist. Third in order were speech and language therapist, occupational or physical therapists, counselor, and social worker. Other professionals were selected to a lesser degree. Overall, the findings in this area support the notion that each family develops a system of resources which it can use to solve the problems it encounters on a day-to-day basis. The more intact the family, the more financial and informal resources it usually has available. Less intact families have a tendency to be isolated and have a smaller resource network or a network made up of more professional people and formal programs and agencies. The reliance on professionals and formal agencies places a family at risk for not effectively leading their day-to-day life. Professionals are not available at all the times that families face problems and professionals often devise solutions which do not maximize the strength of the family in solving their own problems.

The third major issue facing families of disabled children in the 80's is how to use their resource network and resources available in the community to maintain their child at home. One approach taken in Wisconsin has been the creation of Family Support Programs. The goal of Family Support is to provide assistance to families who are facing institutionalizing their child due to the stress on the family. Rather than deciding ahead of time what services are needed, each family is approached as an individual case. Assessment of family needs and resources is conducted and solutions to identified needs are generated with family members. Family Support then provides assistance in implementing the solutions. One family had a six year old son who was labeled autistic and retarded. He was not toilet trained. Mom was expecting a child in six months and felt that she would not be able to continue with two children to diaper. Family Support provided a "trainer" to work with mom implementing a toileting program and a portable toilet which could be used on the first floor of the house where there was not a bathroom. Without Family Support, this child would have been admitted to an institutional based training program for, in all likelihood, three months. The cost difference between the two options clearly favors the Family Support Program.

A second family has a son who was born at 26 weeks gestation, weighing two pounds. He received extensive medical intervention and came home from the hospital after six months. He is hearing impaired, physically handicapped, mentally retarded, and has heart problems. He is considered medically fragile. In many communities his family would have no alternative but to place him in an institutional setting. In Madison, he is enrolled in a four day a week early childhood/special education classroom which includes less handicapped and normal peers. Through Family Support the family has acquired needed equipment for their home. The cost of an institution would be over $40,000 per year. The cost of his public school program and Family Support is less than $7,000 per year.

Families want to be involved in their children's program. They want the child to remain as an important member of the family. Many families cannot do this on their own because the resources they have available are not sufficient. Free public educational programs from birth, and Family Support Programs which capitalize on the family's motivation and skills will help families achieve their goals.

Chairman MILLER. Ann Turnbull is next.

STATEMENT OF ANN P. TURNBULL, ACTING ASSOCIATE DIRECTOR, BUREAU OF CHILD RESEARCH, UNIVERSITY OF KANSAS, LAWRENCE

Ms. TURNBULL. Thank you.

I am very grateful for this opportunity to share my perspectives with you. I am a professor in the department of special education at the University of Kansas and, today, I am speaking on behalf of myself and my husband.

I am a special educator. He is a lawyer. We work in the area of family adjustment and law and policy as it relates to the disabled people.

We also have a son who is 18 years old, who is mentally retarded, and the ideas that I will be sharing with you are those that come from our professional perspectives as well as what we call the living laboratory of our home.

Now, in the research that we have done with families, I want to share with you the fact that often we have been inspired by how well families do. This is a point that Lisbeth just made, that families with children having disabilities have many strengths and many ideas and many coping strategies as well as many stresses.

I would like to focus my remarks on sharing with you some ideas of what I think will help families be successful, and some coping strategies that can, indeed, occur in the least restrictive environment of neighborhoods and communities and family life.

Now, the first point that we have found that is important is just exactly what you have heard so far, that many families that have children with disabilities, have extraordinary needs, and because they have extraordinary needs, their children often are dependent longer and the families end up living in a restricted environment themselves.

It is ironic that often we say we want children to live in the least restrictive environment of the home, and the very fact of the child being in the home often creates a more restrictive environment for the family, and that is not right.

We have identified four or five coping strategies that we think hold a lot of success for the future, and that we would like for you to consider in your deliberations.

I think something I would like to point out here is that money is not everything. Money is important. We must have securely funded programs, but I have found as a parent, and I have found this over time, that I cannot buy personal relationships for him. I cannot buy a certain type of care for him, for if there is one thing that enhances his quality of life and our quality of life, it is when people are involved with him because they want to be, not because they have to be, and for that reason, I think there is tremendous power in social support.

A wonderful experience that we have had is with an adopted grandmother who very much needed grandchildren and wanted grandchildren, and we very much needed a grandmother. And, we got together and we have had a relationship for the last 10 years. This is the relationship that will, I think, withstand the test of time, that when Jay is 30 and 40, Grandma Dot will still be in his life as well as when he is in his adolescence.

She has provided respite care. She has provided the overnights. She has taken him to special events, and when we moved away from her several years ago, it was very traumatic for all of us, but she sends him tapes and she writes him letters, and she sent him a new shirt for Easter.

Those are the things that say to Jay, "You are a valuable person, and there are people who care about you, not because they are your blood relatives, and not because they are paid a salary every week or every month, but because you are a valuable person."

There is another family near our community who used the local football team boys to help them with lifting, bathing, toileting, and dressing, their two sons with muscular dystrophy. The neat thing for the high school sons with muscular dystrophy is that they are helped by peers whom they respect and admire, peers who have status in the high school, peers who have status that they do not have in the high school. The very fact that the football team is interested in them increases their acceptability in the local program.

The football players do that on a day in and day out basis, because they choose to, and it is a wonderful respite for the families, and it builds on the humanness of people caring about people.

Through your policies and through your programs, you can enhance social support. You can enhance programs like foster grandparents. You can encourage Jaycees, 4-H clubs, and other civic groups to care about people in communities who have children with disabilities, and I urge you to take advantage of that power rather than always looking for professionalized services.

Second, we found that many families cope very well through what we call spiritual support. They interpret the disability in a way that they receive spiritual sustenance, spiritual strength, in coming to grips with their responsibilities.

But, we find, from family to family, that often churches and synagogues and communities are not being helpful resources, and, yet, we have examples of one church that provides a wonderful respite care program for families every Wednesday night, free of charge, so the families have a night out and people in the community contribute their time.

You can provide funding to schools of theology to prepare their personnel to use existing community resources, to tack onto what every community has. Every community has a church or a synagogue, but not every community has a formal respite care program or a mental health center. Let us use people caring about people.

Third, there is the coping strategy of what we call reframing. There are many families who take a very difficult situation and are able to see the positives as well as the negatives. But, we do not really understand how that works.

We need to know more about families who are able to translate liability into asset, and disability into ability. That does not mean that children with disabilities are not extra stresses; many times, they are, but we need to help families realize the positives as well as the negatives.

We worked with one mother who had eight children, the youngest of whom had Down syndrome, and she said she was almost relieved when her youngest child had Down syndrome because she did not think she could live through another normal adolescence.

You know, an important point for you to remember is that children with disabilities vary, and they have strengths. They save us from worrying about them when they are driving and into drugs. I mean, there are a lot of stresses they do not create.

So, we are not just talking about problem children. We are talking about children with strengths and children with weaknesses.

And, finally, a coping strategy that is so important for all of us is what you have heard called formal support. We need formal programs, and I could not agree more with the previous speakers about redirecting money to the community and not to institutions.

I urge you to give that your most serious consideration. We do not necessarily need more money at all; we just need it in the place where the most people are and the place where children with disabilities can have the greatest chance for quality of life.

Unquestionably, that is in the community. Help support families that care for their children, rather than supporting three shifts of institutional workers.

We want supported, not substitute, family care, and you can help us get it.

Now, another point that is important is that families are diverse. The two mothers testifying here are quite different from each other, and every other family is different from these two.

The point is that we all have needs, and we all have resources, and if you can create policy that is individualized, so that we are empowered to use the support you can provide in the way that can be most helpful to us.

One example of this is in about one-third of the States, there are voucher programs, so that families are given vouchers to purchase the services that they need. I do not need respite care services. I can get that through my social support network, but I need group homes and job training for my son. So, my needs are different from other parents. If you can look for a policy that is aimed at a voucher type system, you can put the money where the need is.

Another point related to that is often families need help in being consumers. It is hard to be in control of your life. It is easier to fall into the pattern of learned helplessness, of letting government and professionals tell you what to do. We need programs that help families learn how to identify their needs, brainstorm and use their own resources to solve problems, and we can do that. At the University of Kansas, we developed a book for parents called "Tapping the Well Springs: A Problem-Solving Guide for Families" and it is exactly that—helping families know how to tap their own well springs.

Another point is that families need balance. Do not expect parents to do it all. We get so tired of being told that parents can start the programs and parents can advocate and parents can teach their children. We can do that, but if we do, we can burn out and we can resent our child and we do not make the marathon. We wear out in the effort of trying to do it.

So, help us stay the course, and help us have balanced families that can withstand the test of time.

And, my final point is that families change. What we need today is different from what we need next month and next year. We need help in planning for a future that is secure. If you have already heard that Public Law 94-142 is the best thing that has happened to us, and we appreciate your support.

But, there are 90,000 students a year leaving Public Law 94-142 programs. They are leaving the seven course meal of Public Law 94-142 and going back to hamburgers and french fries, at best. There are not adult services, and we are planning for a future that scares us to death.

Now, I want to tell you one last thing, and that is that I just had one of the worst experiences of my life Tuesday night, and it is something that I want you to know about, and it has everything to do with the future of our children.

We are very hopeful and very excited about a new group home for our son. We have worked on every volunteer board. We have been chairman of most of them. We have worried, we have fretted, we have done all of those things about what is going to happen to Jay now that he is eighteen.

But, we have found an option where Jay has the chance to be in what is called a L'Arche group home, a group home based on interdependence, based on value of human life, based on nonhandicapped people living with people having handicaps because they want to, and they want to be a family, rather than a residential alternative.

It is truly the answer to our prayers, or it was until last Tuesday night. The L'Arche home was started by a volunteer board, which had raised all private money, not a penny of government funding for this group home, raising almost $200,000 to buy the house, bought the furniture, got a volunteer board together, and worked with the four adults who will live in the group home and who are not getting paid.

They are living there because they think their life will be enhanced when they share it with people having disabilities. What more could a parent want for a son or daughter?

Well, Tuesday night, the zoning of the L'Arche home came before the city commission in Olathe, KS. Because of zoning laws the issue was one of single-family zoning: Is this a family or is this a business? Well, I can tell you that the L'Arche group home is a family and that is what we wanted for our son.

The board went to the hearing and there was statement after statement. They appealed on the basis of facts, law, and moral rightness. They could not have done a better job. I thought this was the perfect time to have this hearing because the city commission opened its meeting by making proclamations for Exceptional Children's Week. In the proclamation about Exceptional Children's Week, they had a unanimous vote to create, and this is a quote, "the best and brightest opportunity for exceptional people in this community", and I thought how wonderful. They are primed for this issue.

One hour later, when the vote came before the board, the city commission voted 3 to 2 to reject this group home from their community. Now, that was bad enough. I mean, for a parent who worked for it, for a community board who has done it through social support, through grassroot community effort, the blow was almost outstanding, but that was not the worst part.

The worst part was when the mayor said, "I would like to share with you the reason that I voted against this. The reason I voted against this is because my daughter-in-law has a sister-in-law who is one of these people and she knows no bounds and she wanders around the neighborhood and in her neighbor's houses and puts on their clothes, and we cannot have this in our community."

Now, you, distinguished panel, can stop that. If you need and want for us to create programs at the community level, we are willing to do that, but we cannot fight battle after battle of discrimination, not without your help in the United States of America.

For that one woman to say every retarded person is like one retarded person is the ultimate in discrimination. You can look into using Federal housing and civil rights laws to keep us from wasting our time on that kind of prejudice, so we can spend our time on creating quality of life for citizens with disabilities and their families.

Please help us. I implore you to help us with discrimination.

In summary, families can make it. They can make it when they have the extra help and a variety of coping mechanisms, and they can help make it when their individual needs are addressed, when they maintain balance, and when they have a future, when they know that their child's future is secure.

We appreciate what you are doing, and let me assure you as both a parent and a professional, and on behalf of everyone in this room, that there is a tremendous substantial constituency across this land that stands ready and eager to help you make reality equal to the promise and really create a life of opportunity and quality for families and their children.

Thank you very much.

[Prepared statement of Dr. Ann Turnbull follows:]

Prepared Statement of Ann P. Turnbull, Ed.D., The University of Kansas, H. Rutherford Turnbull, LLB, LLM, The University of Kansas

It is an honor to appear before this distinguished committee as it hears testimony concerning the needs of families with children having disabilities. We are grateful for the opportunity.

We are professionals in the field of mental retardation—one of us a special educator and the other a lawyer. We have written a total of 27 books and monographs, 50 chapters, and 75 articles about families, policy, law, and special education in the disability field. We have done work in 43 states and three foreign countries and served as senior officers of the Association for Retarded Citizens of the United States and the American Association on Mental Deficiency. Our research, training, and professional leadership have been forged in the living laboratory of our home. Our 18 year-old son with mental retardation daily provides us with reality tests of our professional work and values. Our testimony to you combines our professional research, training, and leadership as well as our own family life.

We want to share with you four premises about how to help families be successful. We reject the pathology model regarding families that has prevailed too long in the disability field. We want to talk with you about policy and programs that help families not only survive but prevail.

1. FAMILIES NEED HELP IN ATTENDING TO THE EXTRAORDINARY NEEDS OF THEIR CHILD ON A DAY-IN AND DAY-OUT BASIS

Families have responsibilities for meeting many different needs. These needs are in the areas of economic, personal physical care, domestic care, rest and recreation, socialization, self-definition, affection, and educational/vocational. Children vary in the extent to which they influence a family's ability to meet these needs; the primary variables are the type and severity of the disability and the availability or unavailability of community and family resources. It is an established fact that most families have limitations placed on them because their child is more dependent, and remains dependent longer, than other children, solely because of the disability.

Most families value the opportunity for their child to live in the least restrictive environment of the home and family. But they also recognize that their child's living in the least restrictive environment sometimes results in a much more highly restrictive environment for the family. There are many different coping strategies families can use to manage their responsibilities and minimize their stress. We want to discuss four coping strategies very briefly—social support, formal support, spiritual support, and reframing. We believe that these coping strategies are keys to successful family life.

Let us first share with you an example of how social support can help families attend to their extraordinary needs:

Joyce Grosko is a single parent who had two sons, Bryan and Sean. Both were diagnosed during early years as having muscular dystrophy, a disease in which death usually occurs prior to adulthood. As her sons reached adolescence, Joyce was unable to lift them because she is petite and has a herniated disc. She and her sons asked members of the high school council to come to their home in the early morning and again and at night to help with lifting, bathing, toileting, and dressing. The members of the football team voluntered to take on this responsibility. The players learned from the Grosko family a lesson about courage and true-grit that surpassed all others they had ever learned. And the Grosko boys experienced they joy of personal relationships that derive from having friends who help them because they want to rather than because they have to or are paid to. Two years ago the football players served as pallbearers for Bryan and shortly thereafter gave hime a standing ovation when he graduated posthumously from Northwest High School, Shawnee Mission, Kansas.

Many families benefit from assistance in meeting personal care needs. The Groskos were very successful in recruiting volunteer help. Many families, however, face barriers to getting help from their social support networks:

They perceive that the problem is theirs and they alone must solve it;

They fear rejection;

They resist invasion of their privacy (how many of us would want a friend to take us to the bathroom?),

They do not have the time or energy to reciprocate;

They believe it is demeaning and stigmatizing to receive a service they do not pay for;

They are afraid that others will be unable or uncomfortable in handling special needs;

They learn that the help dwindles after the newness wears off.

Wishing these barriers away will not make them disappear. The field of disability has tended to professionalize family services and overlook the wealth of resources in one's own neighborhood and community. We need to capitalize upon the power of social support. You can help families by:

Social Support.—Supporting programs to strengthen social support from extended family, friends, and neighbors. There are many people who are willing to help and many others needing help. We need sparkplug programs to make the connections. Just as programs like foster grandparents have helped develop social support networks, so too can other existing volunteer programs be enlisted to help families (e.g., Scouts, Four-H, Jaycees, and civic clubs).

Another family, the Schaubs, of Lawrence, Kansas, have used a combination of social and formal support in handling their particular situation. Their 13-year old daughter, Becky, is profoundly disabled. She has no language and breathes through a trachesotomy tube. She requires suctioning every three hours. She is not toilet trained. She cannot move her body, only her face, hands, and arms to express herself and give hugs to those she loves. Yet Becky lives at home, at a monthly cost—spent mostly on visiting nurses, physical therapists, and respirator equipment—of $5,000. A high cost, but far less than hospitalization, which her father reports would cost $15,000 monthly. The Schaubs' support comes from a combination of professionals and volunteers. There are the nurses, therapists, and a homebound teacher provided by the public school system. But there also are the church members, neighbors, and friends who have no disabled children as well as friends whose own children are disabled. There are Becky's two sisters, one a college student and the other a junior high school student. Becky's mother stays home, sacrificing her ability to pursue a career and supplement family income as a masters-degree professional. The family's insurance pays the home-based care.

Let's examine this situtation. If Becky's family did not have insurance, their only option would be to institutionalize her, at the average cost to government of approximately $50,000 per year. The Schaubs use a combination of social support (e.g., friends and neighbors) and formal support (e.g., nurses, therapists, and teachers). People like Becky and her family need government sponsored services, as well as the help of their friends.

Our research has convinced us that, as a general rule, families prefer residential and service options that are in the community and not in institutions. The costs of community-based services tend to be lower than those of institutional care, for most people with disabilities and the community is a far better place for human development and satisfaction. Indeed, it is overdue to change Medicaid funding so that it will go where most eligible people are, namely in the community, rather than where the fewest are, in institutions. We need for you to support families to care for their own children rather than supporting three shifts of institutional workers. This is supportive rather than substitute family care. You can help families by:

Residential and Community-Based Options.—Vigorously expanding the options under Medicaid, housing, vocational rehabilitation, and tax laws that will allow families to maintain their children at home or in the community.

Many familes derive tremendous support from their religious and spiritual interpretations of disability.

It helps them find purpose in its occurrance. Examples of such beliefs are these parent statements:

God has a plan for that boy.

In the hereafter, my son will be on equal footing with everyone else.

God has a purpose for our family and is teaching us love and patience.

Our research has indicated a high use of spiritual interpretations and a low use of churches and synogogues as helpful resources. In fact, families have encountered attitudinal, programmatic, and architectual barriers in these organizations. The potential use of churches and synogogues as a helpful resource to families in providing services (e.g., respite care, counseling, transportation, and group homes) is one of our most untapped resources. We have successful models to guide us. A Methodist Church in Shawnee Mission, Kansas provides a respite care program for families. Training has been provided to church members to prepare them to provide care for children with severe and multiple needs. The care is available every Wednesday evening at no cost to families. The church members look forward to helping, the parents eagerly anticipate the break, and the children enjoy their new friends. The minister is available for counseling during this evening time if parents have issues they would like to discuss. This is a beautiful example of using existing community resources and social support to help families meet their needs.

A major barrier is preparation of clergy. In the field of disability we have long recognized the need to prepare community professionals such as classroom teachers and pediatricians to work with families, but we have ignored the vast resource of the clergy. You can help families by:

Training for Community Suppport.—Providing personnel preparation funds to theology schools to prepare clergy to provide support to families.

A final important coping strategy is called reframing. It refers to taking a stressful situation and reinterpreting it in a more positive way. This coping strategy is frequently used by families. For example, Paula Elizondo from Helotes, Texas commented in a letter written to Congress concerning the Baby Doe regulations:

My life and the lives of my family were changed forever on January 18, 1980. At about 6:00 p.m. our daughter Sarah was born. She weighed three pounds. Her diagnosis from the doctors was hopeless, 24 hours to live, deaf, blind, severely retarded.

As I looked at her, fighting to live, held her in the palm of my hands, amazed that this little one was my daughter, hope became eternal for me.

For the next 26 months she taught us more about love, courage, faith and life than most of us could teach or learn in 100 years.

My sons will always have a deep understanding of the hurt that comes with a baby born with problems, but greater, they remember the sweet gentle spirit that was so evident everytime they held Sarah, kissed her smooth soft hands. They have learned that even though she never spoke or laughed, never crawled or walked, she was alive and was loved and brought them joy with her presence.

Obviously Sarah has made profound contributions to the way her family meets their needs for affection and self-definition.

Much of the research literature in the disability field is based on a negtive bias, on a pathology model that asserts that these children are a pervasive burden to their families. Our work with families clearly shows that many families have benefited significantly from their children. They are able to realize positive contributions by reframing disability into ability, liability into asset. We believe that an indepth examination of this coping strategy would provide keys to successful adaptation. You can help families by:

Research on Positive Contributions.—Supporting research and demonstration programs that help families and professionals identify the positive contributions of persons with disabilities. We need to concentrate more on learning from successful families rather than to continue to emphasize pathology.

2. FAMILIES ARE INFINITELY DIVERSE

Families vary in the number of parents, children, and extended family or friends who may be closely involved; in ethnic background, religion, income level, occupation, and location; in the values and beliefs they hold; and in the types of coping strategies they use to manage their responsibilities and reduce their feelings of stress.

Because family characteristics are so different, responses to these characteristics also must vary. A common policy and program assumption is that parents invariably benefit from support groups. Many professionals, therefore, routinely suggest to families that they join such groups.

By quoting from two highly educated, middle-class mothers with similar backgrounds and experiences, we wish to illustrate various attitudes toward support groups. Both mothers were moving from programs with parent support groups to programs that did not have these groups. One mother's response was this:

> I cried for two months last spring. I knew what was going to happen. I didn't know it would be as drastic. I was hoping that there would be some type of parental support but it just didn't happen.

In contrast, another mother's response to the question of what was it like not having a parent group was:

> It is definitely refreshing. You really feel bad for the professionals that want to help you but don't know how. You know, the psychologists and the social workers have this concept that every parent with a handicapped child wants to talk about it all the time—that's garbage!

What works for some families does not work for all. For this very reason (among others), approximately one-third of the states have adopted fairly innovative family support programs. These programs typically offer cash subsidies or vouchers to families to purchase the help that they need—adaptive equipment, medical service, transportation, parent training. The key is that families decide how to spend the subsidy. The evaluation of the program in Minnesota found that the subsidies had a positive effect on the families' abilities to cope with stress. The most desirable direction for policy is to allow families to define their needs and then, by a variety of strategies to support them, empower them to satisfy those needs. Government and professionals should have a facilitating, not a directing, role in helping to respond to those needs. You can help families by:

Options.—Adopting public policy that creates a wider range of acceptable options for families. These options should allow for individualization. The starting point should be the needs and priorities of individual families rather than a pre-formulated package of what every family will be offered.

We have developed a strategy at the University of Kansas that we think has promising implications for families. We recognize that providing policy choices to families requires them to identify and prioritize their own needs. Our experience is that many families have difficulty doing this. In some cases they suffer from "learned helplessness"—they have become dependent on government and professionals to tell them what to do. Along with several of our colleagues, we developed a self-help book entitled "Tapping the Wellsprings: Problem-Solving in Families with Disabled or Chronically Ill Members." The book focuses on the process of problem-solving and helps families capitalize upon and strengthen their own resources to apply to their own specific problems. You can help families by:

Problem Solving.—Supporting programs in the volunteer and professional sector that consist of research and model demonstrations in empowering families to be decision-makers.

3. BALANCE IS A KEY TO SUCCESSFUL FAMILY LIFE

A great deal of educational policy is based on the assumption that parents (as it turns out, usually mothers) should be advocates for and teachers of their children. It has been so easy for policy makers and service providers to say:

> The parents can start new programs. The parents can volunteer in the classroom. The parents can support other parents.

All of these statements are true—the parents can do these things. But what happens to families in the process, and should they be the ones who are totally responsible for addressing all of their child's needs? We will tell you what has happened in our family at times, because it is rather usual for families. We have gotten so involved in advocacy to create necessary programs for Jay that we have not had enough time to be his parents. Rather than leaving him with a child care provider while we go to meeting after meeting devoted to creating programs, he would prefer that we sit together on the sofa, watch Hee Haw on television, and eat popcorn.

Sometimes we fear that children with disabilities lose their parents and gain advocates and teachers. If you were Jay, what kind of adult would you want in your life? We think we know when to pull back; but we pull back with some guilt, because so many people confer the role of advocacy on us as if it were our bounded duty.

Just as we do not expect parents of students without disabilities to be responsible for organizing and securing funding for the college preparatory curriculum in the local high school, we should not expect parents of adolescents with disabilities to organize vocational opportunities for students with disabilities. Yet this assumption exists in communities across this country. Formal professional services are not the answer to all problems. In fact, as we have pointed out, families can derive immeasurable support from friends and neighbors. The point here, however, is that the development of a formal service system is the responsibility of state and local governments and professionals. Families can certainly help, but they cannot be expected to do it single-handedly.

Families are comprised of many simultaneous relationships—husbands and wives, brothers and sisters, parents and children without disabilities, and parents and children with disabilities. Making the child with a disability the focal point of the family is destined to create family problems. We need your help in creating programs that support family balance. You can help families by:

Re-examine Family Duty.—Helping families to make the assumption that their child with a disability will have the same appropriate access to services as children who are not disabled. You can also develop policy that recognizes that parents, wives, husbands, sisters, and brothers have rights to a normal life. We need to support families to be consumers of services, rather than totally consumed by disability.

4. FAMILIES CHANGE OVER THE LIFE CYCLE

Families with young children meet their needs in much different ways than families with older children. Families also have different needs at different times. For example, with young children, families must deal with "breaking the news" to relatives and friends and adjusting to an altered kind of parenthood. But families with young adults must deal with the seemingly endless vista of parental responsibility for an individual who may always be dependent in some ways. And they must make plans to enhance security after they become too old to assume responsibility or die.

We need to recognize that the transitions to a new life-cycle stage are the times of greatest stress. When a child enters school and when he or she leaves it are times of vulnerability in many families. For families with children and youth having disabilities, transitions are usually more difficult because changes are delayed and hard to come by. Families need support in understanding the adolescence of a 16-year-old who is physically mature yet functioning at the preschool developmental stage. The dissonant development creates parental confusion in knowing how to plan for the family's future.

Children who do not experience disabilities move to a new classroom every year, and when they are in junior high school they move every hour. They get used to changes, and so do their parents. But children and youth with disabilities in special class placement may stay in the same class, with the same teacher, for several years. They may never change schools, get a driver's license, go through high school graduation, get married, or leave home—the significant marker events that life moves on. Thus, they become accustomed to routine, and so do their families. Routine is one of the hardest habits to break.

We need to develop intervention strategies to assist families and service providers in looking ahead to the future. What skills will the child need to function successfully in the next class placement? In adult service programs? Are we teaching those skills? What information do families need about the adult residential and vocational programs, and where can they go to find it? Where can families go to find out about guardianship? Wills and trusts? Social security? Options for expressing sexuality?

Parents have been enthusiastic about a program in which we help them work with teachers and adult service providers so their child can make an effective transition from secondary school to adulthood. Among other things, we conduct workshops with families on such legal and ethical issues as estate planning, guardianship, financial resources, sexuality, right to treatment, and case management. Our work will be disseminated through the Association for Retarded Citizens of the United States. You can help families by:

Future Planning.—Supporting research and demonstration programs designed to support families in the process of future planning throughout their life cycle.

Future planning causes all of us to recognize a serious deficiency in our service delivery system. Programs that help families and professionals plan for the future are useful; but so too is policy that declares that the future is useful to plan for. As a nation we have made tremendous strides in the last decade in educating children and youth with disabilities in the public school system. But a frontier of opportunity begging for our attention is transition service for young adults with disabilities. An estimated 90,000 students now receiving special education services will be leaving an educational system that guarantees rights to them and entering the fragmented maze of the adult service system. Where will they work? Where will they live? How much money will they make? Will their income be enough? Where will they get it? We need your help in creating adult services to benefit persons with disabilities and their families.

The Quaker Oats Company has a plant in Lawrence, Kansas, where it packages products and ships them across America. Several years ago, the plant manager entered into a contract with a local sheltered workshop employing people with mild and moderate mental retardation. It was not a contract to provide work for those people in the workshop; instead, it was a contract to bring them into the Quaker Oats plant, put them "on line" with nondisabled workers, and treat them, in all respects except for allowable pay adjustments for work done, as "regular" employees. The plant manager last year accepted the award for Quaker Oats as the "Employer of the Year" from the Association for Retarded Citizens of the United States. In accepting it, he said that the employees with disabilities contributed far more than they earned. They taught other employees how to appreciate the lives they have, how to overcome prejudice, and how to learn and practice acceptance. When the contract ended, the "regular" employees implored him to "bring 'em back" and he did just that, with another contract, and another, and another. Who were the winners? Everyone! And here is the great irony. The plant manager is Sherry Schaub, Becky's Dad. We strongly disagree with the nay-sayers who think Becky has nothing to contribute to society. Look what she did for Sherry and what he and others have done for so many.

You can help families by:

Vocational Training; Employment.—Supporting the preparation of adolescents and adults with disabilities to be tax-payers rather than tax-liabilities, as by providing vocational educational programs. Further, you can help increase public awareness and incentives to business to provide needed job opportunities.

Another major adult service need is the creation of more community living alternatives. These alternatives need to be rooted in the most secure funding possible. Research indicates that the most haunting fear of parents and siblings concerns the child's life after their deaths. Families with children who are disabled face particularly acute existential questions as they ask: What will happen to our children when we die?

This point was brought home very poignantly to us a couple of years ago when a CBS Sunday Morning crew was in our home for several days to film a segment on life in families who have a child with mental retardation. During this series of interviews, we learned something very significant about our daughter, Amy, who was in second-grade at the time.

Late one evening, after watching Amy interacting so naturally and supportively with our son, Jay, the interviewer decided that he wanted to talk with her. He put the microphone around her neck, focused the camera on her, and almost before we knew it asked her: "How do you deal with the fact that your brother is different?" Amy quickly responded that she did not believe that her brother was different: "I like to sing, Jay likes to sing; I like to dance, Jay likes to dance, I think that we are a lot more alike than different." Probably thinking that this was a rather Polly Anna response, the interviewer asked: "Is there anything that you worry that you will get to do in your lifetime that Jay will not get to do because he has a disability?"

Amy thought for a minute and responded, "Yes, there is something that I am very worried about." "I'm really worried that when Jay grows up he will not be able to get a job. And if he doesn't have a job he won't have any money. And if he doesn't have any money he will not have a nice place to live. I am really worried about that."

The CBS interviewer did not quite know how to respond to that comment from a seven-year-old girl, because the tone of her voice clearly indicated that this was of grave concern to her.

After a long pause, Amy added, "But Jay doesn't have to worry about it, because if that happens I will give him my money."

When we asked Amy why she hadn't told us of this concern, she responded, "I did not want you to worry that I am worrying."

Just as concerns about the future pervade families, so too is the need for future security and permanence inextricably linked to families' choice of institutions.

There is desperation in the comments of a parent about his child's institutional placement in Pennhurst:

My child had a broken arm and a tooth knocked out. I wonder what will happen next. But at least I know what it's like here. At least there's some control. What would it be like on the outside? He could wander off and get hit by a car. Who would know; who would care? (Keating, Conroy, Walker, 1980, p. 43).

Another Pennhurst parent spoke to security and permanence in this way:

This community living is great. But what happens when this nice young family (group home supervisors) wants their own family? There might be a psychological let-down if they let them (retarded residents) go. At least Pennhurst was there. It will not crumble (Conroy & Latib, 1982, p. 8).

We all share the interest in reducing stress. We can accomplish almost any goal when families know that their child's future will not crumble and when they can make assumptions that community programs are stable, firmly rooted, and lasting. The public schools are permanent community services for persons with disabilities. That also must be true of residential services and other support across all stages of the life cycle. It is only then that families can live and, yes, die in peace.

You can help families by:

Expanding Community Residential Options.—Creating and expanding secure and permanent community programs for adults with disabilities.

SUMMARY

To live and die in peace, your mind at rest about your children. That is much to ask if you are a parent. But if you are the parent of a child with a disability, it is asking for the extraordinary. And yet the extraordinary can be—and is becoming—the ordinary.

1. Families are attending to the extraordinary needs of their disabled children, in part because you have put programs into place but in part because they reach out and find an empathetic community. The public-private mix is important to maintain, and policy therefore must attend to helping families tack onto the existing community networks.

2. Policy is moving—and you must help it move even faster and more vigorously—toward creating a wider range of acceptable options for families, toward allowing for family choice and individualization. To get there requires Congress to secure more adequate enforcement of federal anti-discrimination law and to maintain and enhance early childhood, special education, vocational rehabilitation, and residential services in the community.

3. Families and professionals are recognizing the need for balancing the competing claims of family members, but they are able to do this nowadays because the panoply of services for their members has not been shredded. Indeed, you have enhanced it. By reauthorizing such laws as the Education of the Handicapped Act, you have made it possible for families to proceed on the assumptions that they may continue to lead balanced lives, contributing to the welfare of all members of their family. We need your continued support, particularly for early intervention and adult services.

4. Families do change over their life-spans. Ordinary transitions for families whose children are not disabled are difficult enough. But they are even more difficult for families who children are disabled. Vocational training, employment opportunities, tax credits and deductions for employing people who are disabled, enforcement of anti-discrimination laws, enlargement of community residential options by using federal housing and social security laws, and assuring the continued viability of the social security funds, are among the ways that you can make the future more attractive.

These are ways that will allow us to live and die with a knowlege that our children, though they are less able, are not less worthy. We are grateful for the opportunity to share our perspectives with you.

Chairman MILLER. Thank you.

Our next witness will be John Butler. Before John begins, let me say to those of you who would like to come into the room, you are welcome to sit down here. We do not have chairs, but if you would like to sit down on the floor or make room in the center aisle, you certainly are welcome to do so, so that you may be able to hear and others may be able to get into the room.

So, please, do not be bashful here.

[Pause.]

Chairman **Miller**. Steve, can you come a little bit forward so that people can get by you? Just like that, if you can.

John, do you have a microphone? OK.

STATEMENT OF JOHN A. BUTLER, COINVESTIGATOR, COLLABORATIVE STUDY OF CHILDREN WITH SPECIAL NEEDS, THE CHILDREN'S HOSPITAL MEDICAL CENTER, BOSTON, MA

Mr. **Butler**. I do not know about the rest of you, but I have been really moved this morning by the combination of Kenneth Mann, George Miller at the award ceremony, and the testimony we have heard so far here. I hope that what I have to say can contribute to that.

Chairman **Miller**. I'm sure it will, if you can speak up a little bit, John.

Mr. **Butler**. Let me also say at the outset that it is really an honor to testify before the Select Committee, both because of the critical bipartisan role that this group can play in focusing the attention of Congress on kids, and also because of the personal role that George Miller and the other Congressmen on the committee have played in furthering the interests of children, youth, and families.

I am John Butler. I am coinvestigator, along with a pediatrician by the name of Judith Palfrey, on a study supported by the Robert Wood Johnson Foundation and the Commonwealth Fund called the Collaborative Study of Children With Special Needs. This is a two-phase study, the first phase of which was a survey conducted in five large school districts around the country, and then the second phase of which is a follow-up we are engaged in now. I will just refer to the first round.

The survey involved identifying a stratified random sample of the elementary school special ed population in Charlotte, NC, Houston, TX, Milwaukee, WI, Santa Clara County, CA, and Rochester, NY. For each of the kids in the sample we performed a parent interview and a record review; a teacher interview was done for half the sample and a physician interview for a subset as well. The intent was to characterize their use of health services, their functional status, and getting some face-valid indicators of how well they were doing in school and adjusting according to their parents and teachers.

That kind of study obviously generates an awful lot of information. I am going to limit my remarks to a very few of our findings, to try to make just three points which have the effect of corroborating from a social scientific standpoint some of what we already have heard this morning.

First of all, we found that many of these families would be under severe stress even without a disabled child because of poverty, low parental education, and single parenthood. This is documented in my written testimomy, but I do not think I ought to read all of the bullets now. In a sense it is belaboring the obvious given what we have already heard this morning. Approximately 50 percent of the families were below 130 percent of Federal poverty standards, except in Santa Clara County. Many of the students' mothers had not graduated from high school, including over 50 percent in two of the districts and over a third in two others. There were very high levels of unemployment, and many of the kids—as many as 60 percent in one of our districts—lived in single-parent households.

So you have a situation here where we think of the handicapped child, and we focus on the handicapped child, but we also ought to acknowledge that there is a tremendous vector of stress on these families independent of the child. That stress interacts with the fact of having a handicapped child.

The second point is that assistance for the families of children with disabilities requires shared effort across many domains, private and public, and not just public education.

I do not wish to offer any kind of apologia for the schools, though I think by and large the schools are doing quite a good job given where they were 10 years ago. But, I do want to urge people to recognize how difficult it is to improve the lives of families with a unitary strategy based on the schools alone. It is really important to think about assistance from various public service sectors and also the private sector, as has been mentioned in some of the previous testimony.

A third major point is that health care access for these children now is far more variable and chancy than access to special education. Those coming from special education may think of access to special ed as chancy, but it is nothing compared to access to health care, and I think some of the testimony we have heard about the costs and out-of-pocket payment, and some of the ironies and catch-22's that parents can get into, have amply supported that view.

In our study, those without a regular physician varied from 14 percent in Santa Clara County and in Rochester (where they still have a very substantial intrastructure of community health centers even though they have much more poverty than Santa Clara County) to a situation which is much worse in some of the other sites. Thirty-seven percent of the kids in Charlotte and in Houston had no regular physicians. Twelve percent of the kids in Charlotte and 27 percent of the kids in Houston had no health insurance at all, and these were across all disability groups.

Given the findings on structural and financial access to care, it also is not surprising that use of health services varied greatly. There was a twofold difference between Santa Clara County and Houston in the percentage of children visiting a physician within the past year, and across all sites, minority group children went to a doctor far less frequently than others. Only 48 percent of Hispanic kids and 51 percent of black kids had a physician visit within the last year as compared to 79 percent of white children.

So, the health care findings really boil down to a sad comment on the differences among States and localities in access to care. Where you live does determine, in large measure, what you are entitled to and what you get, and we also found, consistent with other national data on the entire child population, that minority group children continue to fare more poorly than others, even at a time when Medicaid and other public programs have mitigated economic inequities to a very substantial degree.

Now the policy implications of this are tricky, but it does seem to me that the Medicaid Program and the title V Crippled Children's Program, in particular, need to be better coordinated with 94–142, in both eligibility requirements and implementation. It seems absurd that a low-income Hispanic child in Houston from an intact family, for instance, should receive adequate attention from the schools for his or her educational needs, but be cast adrift without adequate access to even the most basic health services.

Our findings on out-of-pocket payment, which I did not include here, also would curl your hair to see. There is a very high level of out-of-pocket payment by parents, even for those children with the most severe disabilities.

Now, the last point about health care is that the marriage of the health care community and the public education community in implementing Public Law 94–142 really remains at risk and requires, we think, some explicit help and counseling at this point. There remain very substantial disincentives to physician involvement in the program, and that is too bad, because physicians can contribute a lot, and some are looking for ways to do that.

Although in each of the districts we studied there have been a limited number of highly active, involved pediatricians and other doctors, we found that the dominant pattern remained one of ignorance about the intent and procedural guarantees of the Public Law 94–142, and we further found only 30 percent of physicians interviewed were familiar with the child's educational program. Fully 16 percent were completely unaware that the child had an educational handicap.

So, you have got a real problem of boundary spanning here. Given the severe demands on physician time and the economic disincentives to participation in school-based activities, such as IEP conferences, it remains unclear how and to what degree physicians should increase the time they actually spend in schools. But in two regards things clearly could be better. Physicians themselves should know more about the school-related disabilities of children and school programs for the disabled, and likewise, teachers should be given the opportunity to know more about the medical consequences of their students' disabilities.

Just a word about related services, if I can. Much of the responsibility for the coordination of services has fallen on the public health agencies and the schools themselves, especially with regard to the delivery of and payment for related services, such as OT/PT, medical diagnosis, school nursing, and counseling.

Schools and health departments are actually paying for approximately 92 percent of all the speech therapy, 78 percent of all OT/PT, 65 percent of child counseling in the sites that we looked at, and these are large metropolitan areas. By contrast, the role of private health insurance sources in paying for these related services was found to be minimal in all five sites.

So, you have a very substantial effort by the schools and the health departments, but I guess the lamentable conclusion from a policy standpoint is that what you mandate, you end up having to pay for. That is what the schools mandate, the schools and the health departments end up paying for.

Also, among public sector programs there remain some boundary issues because the public health mandates often conflict with public education mandates concerning child eligibility, scope of services, fee schedules, and administrative control. We all are aware of some of the real ironies resulting from either overlaps or gaps in responsibility, where people are not willing to do something in the site of the school because it is not legally the responsibility of the health care people, but, on the other hand, it also is not legally the responsibility of the school people.

These issues are only partially addressed by the recent Tatro decision, and I think there is a lot that remains to be resolved about the appropriate role of the schools in delivering medically related services.

Now, just one final comment, Congressmen, and I will stop. On a personal note, let me say that I, and I suspect a number of others who are less than spiritually perfect here in the group, were deeply offended by the remarks of Eileen Gardner and what they represent. Regardless of the fate of Mrs. Gardner, I think her comments are the tip of the iceberg.

I began to think that maybe I had chosen the wrong aspects of our study to focus on in our testimony this morning because we also have ample evidence, both quantitative and from systematic, key-informant interviews, that the new special education programs are received very positively by parents and teachers, and that within the districts we studied, there really is no zero-sum mentality about special education draining dollars from other areas of public education.

We looked for and did not find any significant perception of competition between special and regular education programs. The special programs were widely accepted and perceived as cost-effective. Also, whatever the cutbacks which have been sustained in recent years—and they have been significant—they have applied to all realms of education, special and regular. Most recently, any new dollars have tended to go toward basic skill and other priorities in general education recommended by recent commission reports, rather than to special education.

In sum, then, the notion of a backlash toward special education just is not evident to any appreciable degree in the districts we have studied, and I would just like to diffuse that shibboleth, if we can do it this morning.

Let me stop there.

[Prepared statement of John Butler follows:]

PREPARED STATEMENT OF JOHN A. BUTLER, CHILDREN'S HOSPITAL, BOSTON, MA

I am grateful for the opportunity to present to the Select Committee some of the findings from the Collaborative Study of Children with Special Needs.

The Collaborative Study conducted a survey in spring of 1983 on a stratified random sample of 1750 children from the elementary school special education programs of five of the nation's largest school systems: Charlotte, NC; Houston, TX; Milwaukee, WI; Rochester, NY; and Santa Clara County, CA. The purpose of the study, which involved parent, teacher and physician interviews as well as reviews of school records, was to characterize the children's use of health services, their functional status, and the perceptions of parents and teachers about their progress in school.

I will focus this morning on our findings regarding serious child and family risk factors and several issues at the intersection of the heatlh care system and the schools. Further detail on these and other aspects of the study is provided in 3 papers which have been submitted as addenda to our testimony.

FAMILY BACKGROUND AND SOURCES OF STRESS

The first thing to understand about children with disabilities in the five school systems we studied is that many of their families, as well as the children themselves, are socioeconomically deprived (Table 1):

Proportions of children below the federal poverty line varied from 43 percent in Rochester to 8 percent in Santa Clara County. Near-poor children constituted a very significant element of the special education population.

Those students whose mothers had not graduated from high school comprised over 50 percent in 2 of the districts (Houston and Rochester), and over one-third in two others (Charlotte and Milwaukee).

There were high levels of unemployment in 4 of the sites—almost half of all the students in Milwaukee and Rochester lived in a family with an unemployed head of household. The rate of unemployment for Charlotte and Houston was approximately 25 percent.

Many children—25 to 60 percent—lived in single-parent households.

The pattern we found does not depart much from the 1983 pattern for the entire school-age population in each of the five urban areas, but in the case of families with a handicapped child the impact of poverty, low parent education, and single parent status was likely to be especially acute, compounding other sources of family stress. Santa Clara County was the only site without a substantial population of families at socioeconomic risk.

We asked parents in our sample whether, because of their child's condition or problem, they ever had to make major changes in their family choices, including where they lived, their job situation, vacation plans, child care arrangements, their marriage, and choice of friends. In the aggregate, 40 percent of the sample reported one or more of these effects. Problems were most prevalent for families with a physically or multiple handicapped child (64 percent), those with an emotionally or behaviorally disturbed child (46 percent), and those with a mentally handicapped youngster (42 percent).

Despite the stress experienced by families with a handicapped child, we were surprised to discover that only 9 percent participated in any form of parent group, only three-fifths said they had an adequate familiarity with community services for their children, and only 11 percent received any kind of family counseling. Contrary to the frequent stereotype of the well-informed, vociferous parent, we discovered parents who were by and large socially isolated, not well-informed, and without adequate supplemental family services.

I also want to emphasize that by investigating only elementary school students we were looking at the best case. The complexities and stresses introduced by having a handicapped adolescent in the family are usually much greater, as are the problems associated with schooling for older students.

HEALTH CARE ACCESS AND USE

Another element of risk for the children in our sample was limited access to health care, especially in several of the school systems, and especially among minority-group students.

There were major differences among the school systems in the percent of children with a regular source of care and regular physician. Those without a regular source varied from 2 percent in Santa Clara County and Rochester to 12 percent in Charlotte and 15 percent in Houston. Those without a regular physician varied from 14 percent in Santa Clara County and Rochester to 37 percent in Charlotte and Houston.

Health insurance coverage—from both private and public sources—also varied dramatically by district (Table 2). Our findings concerning health insurance paralleled those on regular sources of care and regular physicians. Only 7 percent of children in Santa Clara County and Rochester had no insurance, but 12 percent in Charlotte and fully 27 percent in Houston had none. The differences in rates of public insurance coverage were largely explained by variations in state Medicaid eligibility criteria.

Given the findings on structural and financial access to care, it is not surprising that use of health services also varied greatly among sites. There was a two-fold difference between Santa Clara County and Houston in the percent of children visiting a physician within the past year.

Across all sites, minority-group children went to the doctor far less frequently than others—only 48 percent of Hispanc children and 51 percent of Black children had a physician visit within the last year as compared to 79 percent of white children (Figure A).

Our health care findings boil down to a sad comment on differences among states and localities in access to services. Where you live determines in large measure what you get. We also found, consistent with other national data on the entire child population, that minority-group children continue to fare more poorly than others even at a time when Medicaid and other public programs have mitigated economic inequities of access.

PHYSICIAN INVOLVEMENT AND RELATED SERVICES

Because our study focused expressly on the interface between health and education, let me comment briefly on what we found concerning the involvement of health care providers in the implementation of P.L. 94-142. Each of the five school systems had a somewhat different story, but several generalizations are consistent across the sites, reinforcing the view that powerful institutional and professional boundaries still must be overcome if coordination of services is to be improved.

In general, physicians have been only minimally involved with the implementation of the new school-based programs for the handicapped (Figure B). Although in each of the districts there have been a limited number of highly active and involved pediatricians and other doctors, we found that the dominant pattern among physicians remained one of ignorance about the intent and procedural guarantees of P.L. 94-142 and related state law. Only 30 percent of physicians interviewed were familiar with the child's educational program, and 16 percent were completely unaware that the child had an educational handicap.

Given the severe demands on physician time and the economic disincentives to participation in school-based activities such as IEP conferences, it remains unclear how and to what degree physicians should increase the time they spend in schools. But in two regards things clearly could be better. Physicians themselves should know more about the school related disabilities of children and school programs for the disabled. Likewise, teachers should know more about the medical consequences of their students' disabilities.

Much of the responsibility for the coordination of services has fallen on public health agencies and the schools themselves, especially as regards delivery of and payment for related services such as OP/PT, medical diagnosis, school nursing, and counseling. Schools and health departments are actually paying for approximately 92 percent of all speech therapy, 78 percent of all OT/PT, and 65 percent of child counseling. By contrast, the role of private health insurance sources in paying for these related services was found to be minimal in all of the five sites.

Among public sector programs, the main problem is that "boundary" issues arise because public health mandates often conflict with public education mandates concerning child eligibility, scope of services, fee schedules and locus of administrative control.

A particularly disturbing shell game has resulted for children requiring catherterization, tracheal suctioning, and various other medical procedures or forms of medication at school. State laws, regulations and agency guidelines sometimes have resulted in a catch-22 by which no one is empowered or willing to perform certain routine medical services in the school setting. This issue is only partially addressed by the recent *Tatro* decision.

Another aspect or related service which we believe may be inadequate is counseling and mental health serivces for children identified as being emotionally or behaviorally disturbed. Only 50 percent of these children were receiving child counseling, and their parents perceived counseling as a major unmet need. These also were the children whose families experienced greatest socioeconomic stress and family disorganization according to a number of the other indicators included in our study.

POLICY IMPLICATIONS

What are some potential federal policy implications of our findings? We would venture the following ideas aware of the critically important role that the Select Committee can play in coordinating legislative activities on behalf of children across the entire House of Representatives, and the leadership it can exert in the Congress as whole:

(1) Assistance to the families of children with disabilities requires shared effort across the domains of welfare, social service, mental health, health care, developmental disabilities, rehabilitation services, education and other policy domains. We are bumping up against the limit to which the schools alone can be expected to fulfill the promise of Public Law 94-142 in the absence of parallel efforts from other sectors, agencies and programs, both private and public. We do not offer this conclusion as an aplogia for the schools, who can still do much to improve their services, but as a realistic comment on how difficult it is to improve the lives of families with a unitary strategy based in the schools alone.

(2) The Medicaid program and the Title V Crippled Children's Program, in particular, need to be better coordinated with Public Law 94-142 in their eligibility requirements and implementation. It seems absurd, for example, that a low-income Hispanic child in Houston should receive adequate attention from the schools for his or her educational needs but be cast adrift without adequate access to even the most basic health services. In reviewing our data, one cannot help but be struck by the relative consistency of educational eligibility standards and the relative lack of such standards in the health sector. We sit today within a stone's throw of Henry Waxman's district, and all of you are in even closer proximity to his Committee when you return to Washington. Yet surprisingly little is known by his staff about Public Law 94-142, and conversely, little is know about Medicaid by the staff of Select Education and the other Congressional committees with oversight and budgetary responsibility in education. The Select Committee is uniquely positioned to build bridges between these Congressional jurisdictions.

(3) The health care community still does not know with sufficient clarity how to be involved in implementing Public Law 94-142 and parallel state laws. There remains a reservoir of enthusiasm and good will among many physicians and other health care professionals, with frequent calls for more active involvement, but practical and economically feasible mechanisms for physician participation and physician education still are insufficient.

CONCLUSION

It would be wrong to conclude without also mentioning the very positive ratings given to the new special education programs by parents in all of the five school systems studied. Eighty-five percent of the parents in our sample expressed satisfaction with the overall educational program of their child. Likewise, most teachers had a very positive estimation of the progress their handicapped students were making in school. For 75 percent of special needs children, teachers reported improved academic performance during the school year. These facts suggest that, although we still have a long way to go in providing adequate care for disabled children and their families, we also are performing a great service through Public Law 94-142. This legislation remains among the most important national commitments to children, and deserves to be further strengthened and reinforced in coming years.

TABLE 1.—CHARACTERISTICS OF THE SPECIAL EDUCATION POPULATION OF THE FIVE STUDY SITES, 1982-83 SCHOOL YEAR

Characteristics	Study sites				
	Charlotte, NC	Houston, TX	Milwaukee, WI	Rochester, NY	Santa Clara, CA
Ethnicity:					
Percent white	42.8	22.6	38.7	38.2	59.5
Percent black	56.7	44.1	52.9	51.3	5.0
Percent hispanic	0.1	32.6	5.6	9.6	29.5
Percent other	0.4	0.7	2.8	0.9	6.1
Gender: percent male	69.2	66.7	69.1	65.4	64.3
Income: percent students with family income below 130 percent of the poverty line	38	37	45	52	18
Mother's education:					
Percent with less than high school diploma	35.1	52.7	39.3	52.7	23.6
Percent high school graduate	39.1	32.9	41.5	34.2	36.4
Percent above high school diploma	25.8	14.5	19.2	13.1	40.0

TABLE 1.—CHARACTERISTICS OF THE SPECIAL EDUCATION POPULATION OF THE FIVE STUDY SITES, 1982–83 SCHOOL YEAR—Continued

Characteristics	Study sites				
	Charlotte, NC	Houston, TX	Milwaukee, WI	Rochester, NY	Santa Clara, CA
Employment: percent of head of households working full or parttime	77.2	76.9	52.1	52.5	88.3
Living arrangement: percent children with two parents	56.7	64.2	45.6	42.9	76.0

TABLE 2.—HEALTH INSURANCE COVERAGE BY STUDY SITE, CHILD AND FAMILY BACKGROUND CHARACTERISTICS

Characteristic	Type of insurance coverage [1]		
	None	Public	Private
All special education students	12	32	56
Study site:			
Santa Clara County	7	14	79
Rochester	7	52	44
Milwaukee	8	52	41
Charlotte	12	25	62
Houston	27	18	56
Race/ethnicity:			
White	8	19	74
Black	12	50	40
Hispanic	26	20	55
Poverty status:			
Poor	16	67	19
Near poor	16	35	51
Low income	18	21	63
Not poor	4	7	89
Mother's education:			
Non-high school graduate	20	44	37
High school graduate	8	26	68
More than high school	4	18	78
Student handicap:			
High prevalence condition	12	31	57
Low prevalence condition	11	37	55

[1] Percents may add across to more than 100 percent because a student may have both private and public health insurance coverage.

Figure A

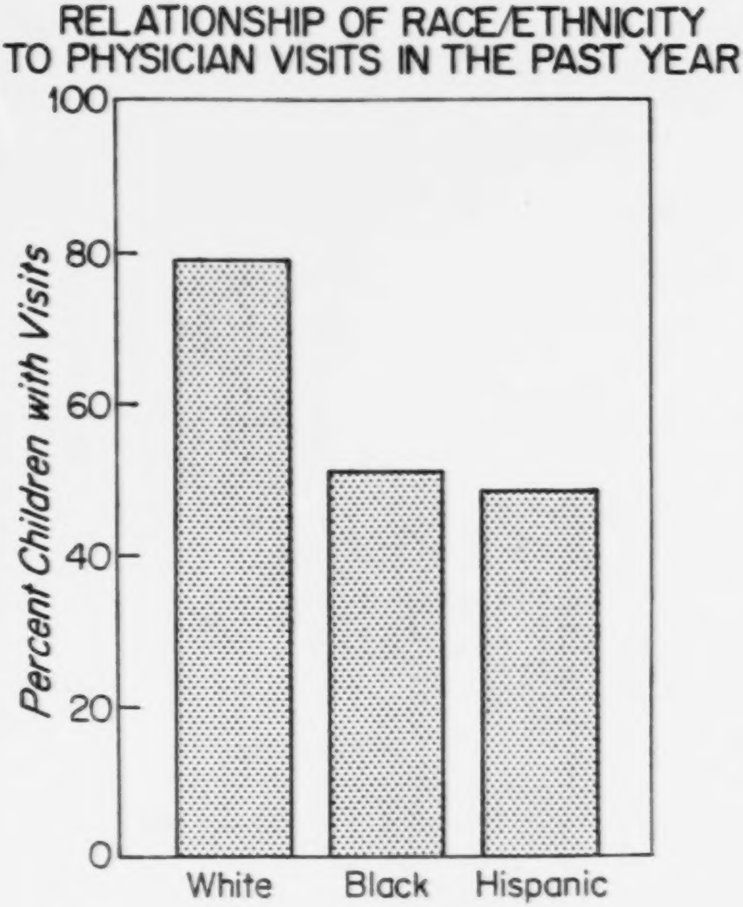
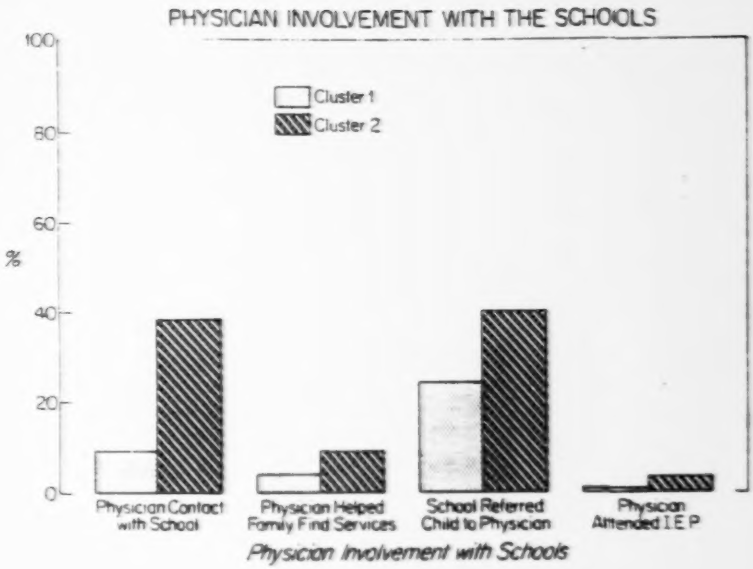

RELATIONSHIP OF RACE/ETHNICITY TO PHYSICIAN VISITS IN THE PAST YEAR
Percent Children with Visits
100
80
60
40
20
0
White
Black
Hispanic

Figure B



Note: Cluster 1 includes children whose primary handicap as reported by parents is speech, learning or other developmental problems, attention deficit disorder or emotional difficulties.

Cluster 2 includes children whose primary handicap as reported by parents is Down Syndrome, hearing or vision problems, cerebral palsy, other neurological problems or general medical conditions.

Chairman **Miller**. Thank you, and let me thank all members of the panel for your testimony. I think you have just been outstanding across the entire panel.

I would like to now begin questioning by members of the congressional panel, Congressman Lehman, do you have questions?

Mr. **Lehman**. Yes. You are the most articulate panel that I can ever remember being before this committee and most other committees that I have served on. You can really tell it like it is.

I do not want you to answer me now, because of the time limit, but, hopefully, those that want to answer these questions can do so by letter or by memorandum to me or to the staff.

For some of the questions I ask, I will be calling on the staff to get me certain information. What I want to deal with is stress and respite, and I think I have an analogy.

I have been involved in South Florida with the hospice program. Now, terminal illness is not a real good subject to relate to, but the hospice program works. I have been out there, and I have seen it, and the people involved in it are a God-send.

Not only do they have an institution that 10 percent of the ill can go to, but in the institution, they have the kinds of visitation privileges and volunteerism that you need for your handicapped children.

But, 90 percent of hospice care is home visitations, and the hospice worker becomes part of the family, but you have to be able to qualify for Medicare to get on the hospice program. Why should we use this good type of an institution just for those that are over 65 and abandon the children that are in a similar type of situation, especially as it relates to the stress on the family and the need of the family for respite.

I guess what I want you to do is to see—to make some kind of a proposal, perhaps, for the committee that would be similar to the kind of programs provided for the terminally ill elderly under the hospice program in regard to the stress of the family and the relief of the stress by the respite services provided by the hospice program. Even in home care, you have emergencies, I am sure, and can always get someone, either a nurse's aide or a type of professional, to come out there and bale them out of their unendurable, temporary situation.

I would like to ask the staff to find out for me, if you can, how this hospice service, in relation to the elderly—how much respite service they get in every hospice program. I think we can push this along those lines.

The other thing I would like to mention is that with the disruptive children in one of our junior high schools in our district, Amelia Earhardt, are assigned to assist handicapped students. This practice not only helps with the handicapped children, but it greatly helps the behaviorial attitudes of disruptive students.

So, I would like to, instead of putting all these disruptive kids in special classes or special schools, why not let them deal with people with other kinds of problems? I would like to have some response on that.

I would like for the staff or you to give us some indication about the diversity of support between the states. I understand California probably has one of the better support systems, but not every State, by far, is like California.

Then, I would like for you or the staff to find out what countries in the world are doing a better job on this kind of a problem than we are doing here, and the one country that I have heard about, and I have not visited, that has the best educational system and the best care for the exceptional child, is one you would not think—it was Yugoslavia.

Now, I do not know whether that is still true or whether the gentleman was telling me the truth or not, but if—good deeds are where you find them, and good systems are where you find them, and it may be in Scandinavia, it may be in West Germany, it may be in Ireland, I do not know, but I do not think that this country should have the second best support system for the parents and the children, the parents that are handicapped or the children that are handicapped. I would like to know if either the staff or yourselves can find a model in some other country that we can hold up as a goal that we should imitate.

I want to thank the chairman for calling this session together, and this hearing, and I think it has been very worthwhile, and I hope it can lead to some solutions for your problems.

Ms. TURNBULL. Would you allow us to return the compliment and say those are some of the most articulate suggestions that we have heard, too?

Mr. LEHMAN. Thank you. I am not as articulate as I used to be. I had an operation a couple of years ago for a tumor on the side of my jaw here, and they cut all the nerves in one side. Everything is dead on one side of my tongue and my jaw. So, I always say I am now the—by the way, I am all right, and I do not have any recurrence, but I always say I am the only politician to even if he wanted to could only talk out of one side of his mouth. [Laughter.]

Chairman MILLER. Barbara?

Ms. VUCANOVICH. Thank you, Mr. Chairman, and I do have one housekeeping chore. I would like to ask that the record be kept open for 3 days in order to receive the testimony of Madeline Will, who is assistant secretary for special education and for Margaret Burley, if I may.

Chairman MILLER. Yes. We will hold it open until May 3.

Ms. VUCANOVICH. Thank you. I have a couple of questions for some of the panelists, and, by the way, I congratulate all of you. It was just a very special thing to all of us because we have heard lots of stories, but I do not think we have heard anything of more compassionate people and more caring people.

But, I would like to mention to Mr. Butler, and I am sure that he is aware that both Mrs. Gardner and Mr. Uzzell have resigned this morning——

Mr. BUTLER. Yes.

Ms. VUCANOVICH [continuing]. And their names were withdrawn, and I think that is a very positive thing, and I think that we ought to applaud that happening. [Applause.]

I particularly would like to comment to Mrs. Turnbull. I—my husband was married before and has a retarded son, who is now 23 or 24 years old, and most of the things that you have talked about, I have faced, too, having been married now about 19 years, and have had to deal with the young man who is now 23, and it is a problem.

I really think my question to you, we have had the same experience about a home being provided and done through private industry and donations and had not only the city councils turn the home down, but also people in communities, and object to the fact that retarded people would be in the community or handicapped people.

I just wonder if you do have any suggestions. How do you change public attitudes so that people are really less afraid, and more willing to reach out to families? And, I think it is the family situation.

Ms. **Turnbull**. I am glad you asked that.

I think that there are several ways we can do it. I think the first thing we can do is to stop always relying on professionals and families to be the ones who are involved with people with disabilities. What you and I know as mothers is that our children have taught us that there is value in difference, and that they have made us less selfish and more sensitive to human need because we have lived with them and we have interacted with them.

That is one of their gifts to us. Now, they can share that gift with us and they can share it with their teachers, but if they are not around other people in the community, they cannot teach that lesson to others.

I think when we use social support, when we rely on friends and neighbors and civic groups and people in the community, they have an opportunity to learn that people with disabilities are valuable and have many assets.

Also, when we dismantle our institutions and bring these citizens back to the community, they become visible, and we know that people who are out of sight are often out of mind. We need to have that community presence.

When we get churches and synagogues involved, that is where many people are. Not everyone is there, and certainly that does not mean that everyone should be religious. But, the fact remains that there is a great public awareness contribution that churches and synagogues can make, but, so often, we pay respite care providers and we do not encourage the church to be respite care providers, to get sensitive to this issue, to teach them about their congregation.

But, let me share with you one other thing because I think this is the direction I want to go for the next couple of years. My daughter, who is 9-years-old and in fourth grade, chose this year for a science project to test the effectiveness of whether she could increase the positive attitudes of second graders toward children who are retarded.

Now, Amy would not choose to do a science project by choice. I mean to do one on energy or the weather——

Ms. **Vucanovich**. Remarkable.

Ms. **Turnbull** [continuing]. Would just bore her to tears, you know. So, there was a selfish motive in this, too. But, she is very concerned about this because of her brother.

Now, again, that is a contribution that Jay has made to her, and it is, again, that point about sensitivity.

She took two second grade classes, she tested them both with the test on attitudes. She herself developed a 50-minute lesson on mental retardation, told them the point of the view of the kid, and taught the one class, and then she went back and tested both classes, and she found a highly significant increase, a highly significant increase in positive attitudes of the children she taught. Fifty minutes, a highly significant increase—it could have been a master's thesis. Why did she not give it to me 15 years ago?

But, this is the point. In her conclusions section, she said she thought the reason that this happens was because kids look up to older kids: Second graders look up to fourth graders, but they do not necessarily look up to their teachers.

Ms. VUCANOVICH. Oh, that is amazing.

Ms. TURNBULL. And, that she could influence second graders about how to think, because they know her and they respect her, and she is an upper classman.

And, second, she said that she used the words of a child and she said adults complicate things. Now, let me give you a quick example.

When she explained mental retardation, she used the Michael Jackson "Thriller" record, and she put Michael Jackson "Thriller" on the slow speed, and she said some people have brains that work slowly. She put Michael Jackson "Thriller" on the fast speed, and she said and other people have brains that work fast. She said, "But kids, the important thing for you to learn today is that it plays "Thriller" on both speeds."

Then, she said to us, "You know, maybe if kids could take more responsibility from an earlier age and talk to other children in the language that is in the heart of a child, maybe the group home zoning would pass the next time around."

Ms. VUCANOVICH. That is beautiful.

Ms. TURNBULL. So, I really think that there is power in that we need to start from the earliest age. We need to involve children having interpersonal relationships with other children. We need to have a presence of these people in the community, and things will change. They are already so much better than they were 10 years ago.

Ms. VUCANOVICH. Thank you very much, and I know other members of the panel have questions to ask. So, thank you all very much.

Chairman MILLER. Mr. Evans.

Mr. EVANS. I thank you, Mr. Chairman.

I would like to address two problems I saw in the first two witnesses' testimony. The attitudes of professionals or alleged professionals, is, Mary, my problem with the D.A.'s opinion. Instead of telling you that $87.50 a week is too high, the county should have been telling her husband to bring his toothbrush because he is going to end up in the county jail, if he does not want to pay. That is a problem that was prevalent 2 years ago, when I was a legal aid attorney.

And, it is a problem, I think, we continue to see. Not only for the families of handicapped children, but families of other children as well. It is something we have tried to address in terms of a few bills that we had just in the child support area, but I also think it is a problem of the legal profession, particularly the people in charge of carrying out the law, enforcing the law.

If they have that attitude, you cannot even get your case before a judge.

Ms. **Short**. One of the most bizarre things about him being on probation is we have not spoken to one another since March of 1982. Occasionally, I see his truck, he sees my car, you know, so we pass each other.

I asked the probation department for his address so that I could serve him, take him back to court on an OSC, to reduce the child support. They cannot give me his address. But, when he goes off probation, they will send a letter to him telling him to send his money to me at my address and they will send me a copy of that letter, with his address on it. Fine.

Chairman **Miller**. That is Orange County.

Ms. **Short**. Stress. I am supposed to deal with that kind of support from the system. Anyway, so I am waiting for December 17, till I get his address. It is fine. The system.

Mr. **Evans**. We have always had this notion in American jurisprudence, that justice delayed is justice denied. And, for a child to get—to wait 2 years of due process hearing . . . particularly, in the case of a person with handicaps, that need the help at an early age seems to me to be a delay of justice that leads to a denial of Justice.

Beverly, why did that happen?

Ms. **Bertaina**. Well, it did not take that long for the due process hearing; it was the whole process.

Mr. **Evans**. I see.

Ms. **Bertaina**. Starting out getting assessments, fighting through the IEP, convincing them that they really did have to obey the law, and then finally for them to start the program.

My son was in the first integrated SH class in Sonoma County, and because we dragged six other kids out with him, out from the development center, due process hearing, you know, the whole procedure was only a piece of the 2 years, and it is a long process for any—getting any kind of services for these kids.

Complaints to the office of civil rights. Parents have given up even trying that anymore because of a very poor response.

Mr. **Evans**. What is the availability of legal services? Do you have legal aid clinics that assist?

Ms. **Bertaina**. No; we had, at that time, that we were doing this, there was an advocate working at Berkeley, at the Center for Independent Living. I used to work at that parent advocacy unit there, and we provided a lot of advocacy.

We lost our grant. Grants have been cut all over the place. There is very little advocacy. In Sonoma County now, UCP, United Cerebral Palsy, is the only organization providing any kind of consistent advocacy for parents, and they cannot do it all.

No, there are very few legal services there.

Mr. **Evans**. Do you have a central place?

Ms. **Short**. Yes; the whole IEP system is very difficult to deal with, and when you get to the fair hearing level, unless you do qualify for legal aid, or one of the agencies that has some sort of legal advocate decides to help you, the parent ends up attempting to pay for it on their own or trying to go through it without any training, and you need an attorney. I work for an attorney. He will not help me.

Mr. **Evans**. The school board is going to have——

Ms. **Short**. An attorney.

Mr. **Evans**. If it goes higher, they are going to have an attorney in the appeal process. I know that from my own experience. There have been delays as well. We had a problem in the State of Illinois where they did not have the regulation on the State basis for a year after they were mandated to have the regulations.

So, this was 3 years ago, and I think it is a problem that we need to look into to make sure that the State is following through——

Ms. **Bertaina**. This happened about 4 years ago. Started about 4 years ago.

Mr. **Evans**. All right.

Ms. **Bertaina**. But, in California, I think, they recently passed a law that said, if I am remembering correctly, that parents may not bring an attorney to an IEP meeting unless—no, excuse me. The district will not pay for the attorney unless they use one themselves.

There is some—I cannot remember exactly how it goes, but it limits the parents' right to legal assistance, you know, within IEP and within fair hearing procedures. It is a real problem.

Mr. **Evans**. Is there any other panel—you will have to move the microphone down so we can get it in the record.

Ms. **Vincent**. I really want to comment on the due process and IEP system from the perspective of the changing American families.

We have two very articulate parents over here and another one over here, and Ann will tell you, she probably has written the best book there is on how to write an IEP as a professional. It has 17 chapters and checklists, and we all used it with our students, and she will tell you, when she goes into Jay's IEP meeting, she forgets all of her questions, she cannot get the information asked.

And, what I want to point out about due process and was very sad about that is that many, many of the families that I work with are very dissatisfied with their children's services, but they do not have the self-confidence, the educational background, the tenacity, the willingness to have everybody in the public school not like them in order to take the process on. They really need advocates and the systems out there need to have advocate people available, other parents who have gone through the process, because it is very few parents that can really take the system on. Many of the parents who most need the services are the very people that don't take the system on. I talked with a father the other day on the phone, and he said—I said, well, you did not sign the IEP, and he said, I just—I cannot deal with them anymore. I just signed it and I will work on what needs to be worked on at home, you know, and I think that is a very sad situation.

Mr. **Butler**. Just a really very quick comment.

Mr. **Evans**. Can you move the microphone down?

Mr. **Butler**. Yes; I have some evidence that supported the same point. In our study, we asked parents whether they had attended the most recent IEP conference, and in Santa Clara County, which was by far the most affluent of our sites, 90 percent had, in part because they had the disposable income and time to be able to attend, and in part because the school system had made special arrangements to hold the hearings at hours when they could attend.

In the other districts, attendance was more like 50 percent, for all the opposite reasons plus the intimidation factor and so on. You have a law which, in its procedural guarantees, is about as complicated as anything you or I could understand, and then you have parents 50 percent of whom have not graduated from high school being asked to come in and fight for their rights.

I do not think we should back away from those procedural guarantees. I think they are terribly important, but I think we should provide the families sufficient support to be able to fulfill the intent of those guarantees, and that may mean doing more than we are currently doing for those families.

Mr. EVANS. I do not want to overdo my time here, but if any of you could give me some studies or some things that have been done on how we could, and what the cost would be, to shift the resources from an institutional to an individual level, I would like to have some of those studies. Thank you.

Mr. MONSON. Thank you, Mr. Chairman.

I have appreciated very much the testimony we have heard here today, too, and I think it has helped us all recognize the value of a solid family support for these situations, and, yet, pointed out that there are other problems out there still that need to be dealt with.

Dr. Vincent, you suggested that we need to mandate to state and local education agencies to assume responsibility for the handicapped child's educational program from the point the child is diagnosed.

You also indicated that you do not think we need to put more money into the solving the problems. Is this going to require putting more money into solving the problems?

Ms. VINCENT. I think the issue, and it is one that several of us have spoken to, is who gets to spend the money. We have a program in Wisconsin called the Wisconsin Family Support Program, which is on a pilot basis, and through that program, families can apply for up to $200 a month to maintain their child at home, rather than institutionalizing them, and as part of that, what we have done is work with community agencies to provide day care and full day programs for children under five, family supporting, and one of the things that we saw is that for every child we keep out of the institution in Wisconsin, because our institutions are about $50,000 a year, we could pay for early intervention services for 15 to 25 children in the community.

Now, it is not the same pot of money. We are talking about taking money from health and social services and moving it into education.

But, I think the reality is that most of our data said that when early intervention is available from birth, communities do not as highly institutionalize children.

Our school district has served children from birth for the last 10 years, although we are not mandated to do so. Our district is doing it as local choice on local dollars. We have not institutionalized a single child under 6 years of age from our city in the last 10 years.

So, not a single child has been placed, and that is an enormous cost savings, which then can go into education.

Mr. **Monson**. Well, I just wanted to clarify that point because one of the cost concerns that we hear from local officials is that we always are mandating them to do things without providing funding for them to do it.

Ms. **Vincent**. Right.

Mr. **Monson**. And, I want to make sure that if we do that kind of thing, that we provide a means to take——

Ms. **Vincent**. We are going to have to take money from one pot and put that money over and put it into the community, and into families maintaining their children at home.

Mr. **Monson**. There is a lot of other questions I think that should be asked, but I think in the interests of time, I will have to save them.

I just want to again compliment you all and appreciate the evidence that has been presented here on some of the opportunities that are available. I wish that everywhere had those same opportunities, but at least it gives us some encouragement that maybe we can find ways to get those started in every place.

Thank you very much.

Chairman **Miller**. Thank you.

Let me again compliment the panel. In response to the dialog with Congressman Evans, let me say that the issue of attorney's fees and representation is being fought hard right now in the Education and Labor Committee. The decision about attorney's fees will really determine whether there is a mismatch between parent and schools in most hearings.

I speak from the experience of my own congressional district. Had they provided attorneys and worked things out earlier, they would not have lost a considerable amount of Federal moneys by violating the law, and parents would have known that attorneys could represent them. They went through a very disheartening experience, as the Federal dollars dried up for a considerable period of time.

On the issue of deinstitutionalization and prevention, I think, again, that both 94-142 and the foster care legislation have shown that certain services, in fact, reduce costs. We now see the number of children going into foster care dramatically reduced throughout the country, even as demand for foster care has gone up. We see the number of children in permanent placements through adoption. We learned that we could trade the provision of services to families to help children from being placed, and thereby save moneys in the long term as well. I think that is the issue that is now being raised here.

I do not know whether in this case, it will prove to require more or less, or the same amount of funds. But, clearly, we have got to ask ourselves what kind of system is it that is biased against a family trying to take care of its own.

This committee was created to try to strengthen the fundamental institution in America, the family. We have tried at each hearing to see how we can spend whatever dollars we are spending in a different manner, so as to strengthen that institution.

In Mr. Monson's State, Utah, they tried a child care experiment, to see if they could reduce AFDC payments, and they found, I think, even in the middle of the recession, that their AFDC payments were dropping as they provided child care to single parents who wanted to go out and get a job. Perhaps, we should revisit this subject with the idea that, in many instances, intervention and prevention services will reduce the cost of what government ultimately pays.

You have given us an awful lot of things to think about. I appreciate your testimony and your time, and all of your effort, and I would hope that you would continue to stay in touch with the committee.

So, thank you very much.

Ms. **Vincent**. May I make one brief point.

Chairman **Miller**. Somehow I thought maybe you would.

Ms. **Vincent**. I am——

Chairman **Miller**. I am supposed to be a powerful chairman of a powerful committee, you know, and——

Ms. **Vincent**. What you heard from this panel is very consistent with the priorities of Mrs. Madeline Will. Her priorities are early intervention, transition, family support and community integration, and, so, I think as you work with her in that executive agency, keep in mind that those priorities are what we have been talking about this morning.

Chairman **Miller**. We are going to match Ms. Will up with the President. When he was Governor, he wanted to start community-based mental health facilities, so we closed the other institutions. We then forgot about building community programs. So, we are going to revisit this and maybe with Ms. Will's help, we will get it all straightened out here.

Ms. **Vincent**. Thank you.

Chairman **Miller**. Thank you very much.

We will begin the next panel. Steven, you are already here.

[Pause.]

Chairman **Miller**. We need Trudy Latzko, who is the program director of Developmental Services Department for the city of San Francisco, and Florene Poyadue, who is a parent and executive director of Parents Helping Parents, and Betsy Anderson's testimony will be given by Martha Ziegler, who is the head of the Federation for children with Special Needs. We will be ready to go here in a moment.

[Pause.]

STATEMENT OF STEPHEN BREES, CONSULTANT, FOUNTAIN VALLEY SCHOOL DISTRICT, FOUNTAIN VALLEY, CA

Mr. **Brees**. Thank you for giving me the honor——

Chairman **Miller**. Excuse me. We are going to have to ask that everyone be especially quiet so that we can hear the witnesses. Go ahead.

Mr. **Brees**. Thank you for giving me the honor of appearing before you, especially since I tried to just upstage you. I hope I can convey useful information about specific aspects of my educational, economic and employment experiences.

I am 32 years old. My disability is cerebral palsy. Shortly after my disability was diagnosed, I began attending a special education school located here in Orange County. I attended this school from the age of 3 to 16, during which time I received physical therapy, assistance meeting my physical needs, recreational experiences, and educational training.

All of the pupils who attended this school were, in one way or another, physically and/or learning disabled. With the encouragement and support of both my parents and the very special special education teacher, I began to attend a regular high school at the age of 16.

Although there was a home room in which I received assistance with such things as changing my clothes for PE and meeting toilet needs, for the most part, my experiences in high school centered around interactions with nondisabled students, both academically and socially.

It was during these challenging high school years that I became interested in psychology, and I have stayed on the track because I just received a master's degree in counseling last summer from California State University at Fullerton.

I require physical assistance with my personal needs on a daily basis. Some of the important and fundamental tasks I need help with are transferring in and out of bed, transferring on and off the toilet, personal hygiene, and dressing. These needs are fundamental and primary, because unless these needs are met, I cannot function very well, if at all, at school or on the job.

My first opportunity to live independently came when I attended the University of California at Riverside, where I received my B.A. in sociology. For approximately 4 years, I lived in the dormitories there. I then lived in an apartment subsidized by Housing and Urban Development, which was within walking distance of the university.

The entire campus as well as the dorm had specific modifications which made living there much easier, and that was funded by Project Hope.

It was at UCR that I first learned how to locate, hire, and train those persons who were to help me meet my physical needs. These people I call attendants. Newspaper ads, disabled student services offices at different colleges, community services, service agencies serving the needs of the disabled, and word of mouth have been the most effective methods that I have found in locating attendants.

However, I have often found that I have had an insufficient number of responsible people from which to choose when hiring an attendant. Part of the reason for this is economic in nature. The salary of my attendants, until just recently, has been provided solely by a county/State program entitled "In-Home Supportive Services."

While this program has been very helpful, it is averaged out to a daily rate of from $15 to $17 per day, and at the very least, I require an average of 5 hours of physical assistance daily.

According to the rules of the program, if I earn money to supplement this amount, the amount granted to me is reduced. I cannot offer a potentially desirable employee an economically competitive remuneration. As a result, the people I do tend to deal with are often nonprofessional, untrained, and less than totally responsible.

Until recently, I have been receiving supplemental security income from the Social Security Administration. This SSI has been granted to me with the stipulation that I do not engage in significant gainful employment. As I have mentioned previously, I have a master's degree in counseling.

My future long-term goal is to become a practicing marriage, family, and child counselor. In order to do this, I must do volunteer work in the community in order to get the supervised hours necessary to get the license. In order to do my field work, I must rely on attendants.

In order to acquire the services of attendants, I must pay them more than the amount allotted by the Government. In order to pay my attendants, adequately, therefore, I must find a job which pays more than the sum total of Government assistance.

While I believe that a disabled person who has had a successful employment history should make provisions for the expenses commensurate with his or her physical needs, I also believe that successful working habits are learned, and if you have not had an opportunity to develop those habits, it is hard to act accordingly.

Positive work habits are developed, in part, from having a history of experiences in which a child can learn how to gradually assume responsibility for himself as he matures.

I am well aware that many people have limited capacities to take care of themselves or to be employed, let alone to live independently. However, must children, disabled people, and retired folks, be employed in order to be of social benefit?

I am convinced that whatever social benefits I may be to my community is largely possible because of the relationships I have had and still have in educational and vocational settings.

My current employment status is new and exciting. I am a consultant for the Fountain Valley School District here in California. I am taking part in the development of curriculums to familiarize second and fifth grade children with other children in their school who have disabilities.

My position will last, 3 months. It pays well enough for me to meet my expenses and have enough left over to look for another job. I needed a master's degree before I could afford to discontinue supplemental security income, and before I could afford to have my attendant care governmental allotment greatly reduced.

I needed a master's degree before I could economically afford to be gainfully employed.

In closing, I have the following general recommendations:

With respect to special education, it is important to educate as much of the child as possible. By that, I mean to plan for his intellectual and emotional development, however limited that may be, in addition to his physical development.

Second, establish or work in conjunction with already existing agencies which provide information for the disabled person and for parents of the disabled on attendant care, accessible housing, transportation options, health insurance, et cetera.

Third, provide grants to establish attendant care training programs.

Fourth, provide safe, reliable transportation for disabled people.

And, fifth, consider providing economic assistance to people with disabilities—based more on their actual physical needs and less on their employment histories.

I would like to thank you very much for your attention, and I would like to make myself available to you to answer any questions you may have in the future.

I really appreciate being able to come here.

Chairman **Miller**. Thank you, Steve, very much.

[Prepared statement of Stephen Robert Brees follows:]

PREPARED STATEMENT OF STEPHEN ROBERT BREES

Thank you for giving me the honor of appearing before you. I hope I can convey useful information about specific aspects of my educational, economic and employment experiences.

I am 32 years old. My disability is cerebral palsy.

Shortly after my disability was diagnosed, I began attending a Special Education school located here in Orange County. I attended this school from the age of three to sixteen, during which time I received physical therapy, assistance meeting my physical needs, recreational experiences and educational training. All of the pupils who attended this school were in one way or another physically and/or learning disabled.

With the encouragement and support of both of my parents and a very special Special Education teacher, I began to attend a "regular" high school at the age of 16. Although there was a home room in which I received assistance with such things as changing for adaptive P.E., and meeting toilet needs, for the most part my experiences in high school centered around interactions with non-disabled students both academically and socially. It was during these challenging high school years that I became interested in psychology. I received a Masters Degree in Psychology last summer from California State University at Fullerton.

I require physical assistance with my personal needs on a daily basis. Some of the important and fundamental tasks I need help with are transferring in and out of bed, transferring on and off the toilet, personal hygiene and dressing. These needs are fundamental and primary because unless these needs are met, I can not function very well, if at all, at school or on the job.

My first opportunity to live independently came when I attended the University of California at Riverside. For approximately four years I lived in the dormitories there. I then lived in an apartment, subsidized by H.U.D., which was within walking distance of the university. The entire campus as well as the dorm had specific modifications which made living there easier.

It was at UCR that I first learned how to locate, hire and train those persons who were to help me meet my physical needs. Newspaper ads, disabled student services offices at different colleges, community services serving the needs of the disabled, and word of mouth have been the most effective methods that I have found of locating attendants. However, I have often found that I have had an insufficient number of responsible people from which to choose when hiring an attendant. Part of the reason for this is economic in nature. The salary of my attendants until just recently has been provided solely by a county/state program entitled In Home Supportive Services. While the program has been very helpful, it has averaged out to a daily rate of from $15 to $17 per day. At the very least I require an average of five hours of assistance daily. According to the rules of the program, if I earn money to supplement this amount, the amount granted to me is reduced. I cannot offer potentially desireable employees an economically competitive remuneration. As a result, the people I do tend to deal with are often non-professional, untrained, less than totally responsible people.

Until recently I have been receiving Supplemental Security Income from the Social Security Administration. This SSI has been granted to me with the stipulation that I do not engage in significant gainful employment. As I mentioned previously, I have a Masters degree in counseling. My future long term goal is to become a practicing marriage, family and child counselor. In order to do this, I must do volunteer field work in the community. In order to do my field work, I must rely on attendants. In order to acquire the services of attendants, I must pay them more than the amount allotted by the government. In order to pay my attendants adequately, I must find a job which pays more than the sum total of governmental assistance. I need to make enough money to make it worth being gainfully employed.

While I believe that a disabled person who has had a successful employment history should make provisions for the expenses commensurate with his or her physical needs, I also believe that successful work habits are learned. Positive work habits are developed in part from having a history of experiences in which a child can learn how to gradually assume responsibility for himself as he matures. I am well aware that many people have limited capacities to take care of themselves or to be employed, let alone to live independently, however, must children, disabled people and retired folk be employed in order to be of social benefit. I am convinced that whatever social benefit I may be to my community is largely possible because of the relationship I have had and still have in education and vocational settings.

My current employment status is new and exciting. I am a consultant for the Fountain Valley School District here in California. I am taking part in the development of curricula to familiarize second and fifth grade children with other children who have disabilities. My position will last two months. It pays well enough for me to meet my expenses and have enough left over to look for another job. I needed a Masters degree before I could afford to discontinue Supplemental Security Income and before I could afford to have my attendant care greatly reduced. I needed a Masters degree before I could economically afford to be gainfully employed.

In closing I have the following general recommendations:

1. With respect to special education it is important to educate as much of the child as possible. By that I mean to plan for his intellectual and emotional development however limited that may be in addition to his physical development.
2. Establish or work in conjunction with already existing agencies which provide information for the disabled on attendant care, accessible housing, transportation options, health insurance, etc.
3. Provide grants to establish attendant care training programs.
4. Provide safe reliable public transportation for disabled people.
5. Consider providing economic assistance to people with disabilities based on more on actual physical needs and less on their employment histories.

I would like to thank you very much for your attention and I would like to offer to make myself available to anwer any questions you may have.

STATEMENT OF TRUDY LATZKO, PROGRAM DIRECTOR OF DEVELOPMENTAL SERVICES DEPARTMENT, FAMILY SERVICE AGENCY OF SAN FRANCISCO, SAN FRANCISCO, CA

Ms. LATZKO. Chairman Miller and other committee members, I, too, appreciate your giving me this opportunity to give my presentation today.

As the program director of the developmental services department of the Family Service Agency in San Francisco, I have been asked to describe the services that we offer to children from 2 weeks to 3 years old. I understand that I am probably going to be the only one who will be talking about these earliest intervention programs.

Before I do that, I would like to express my professional and personal opinion, based on 25 years of experience as a nurse and as a program administrator, that parents of young disabled children, as we have heard so articulately this morning, need to have options open to them. The programs directed toward these children need to be individualized as the options given to parents need to be individualized.

One cannot think about the child in isolation. Many infant programs, even here in California where there are many good programs, plan for the child's needs without thinking of the child in relationship to his family. My presentation will be directed toward the needs of the family.

Most programs for children under 3 years old have traditionally been designed to offer assistance to families through home visits or center sessions, during which the families observe with and work with professionals in order to learn to implement therapeutic activities with their children. They observe these activities and implement them at home. These sessions last 1 to 2 hours at a time, 1 to 3 days a week. This type of program is ideal for families in which one parent does not work, and he or she is able to carry out these activities at home. But the reality of life today is that women do need to work. We know from statistics that half of the women with children under 6 years old work. They work because most of them need to earn the money to support their families.

Other families may not be highly functioning, especially in today's society. We cannot depend upon these families being able to carry out professional suggestions. Even though the programs that are available may offer excellent services, they do not meet the needs of these families. I would like to give you a few examples taken directly from the families that we serve.

A 14-year-old mother, whose child has a severe metabolic disorder—maple syrup urine disease. This mother needs to finish school. She has to finish junior high, and to go on to high school. Her family speaks only Spanish.

A family in which the father is periodically unemployed. He has just recently had a stroke. The mother's job is essential to support three children, the youngest of whom is severely disabled.

A single parent who drank heavily before she knew she was pregnant. She is receiving therapy for alcoholism, and the natural kind of guilt that she feels toward her child who has fetal alcohol syndrome.

These are just three examples. I could give you examples of every single family that we serve because our services are designed for the highest risk families. None of these families would benefit from a traditional program.

Now, I am going to describe a little bit about our program. Family Developmental Center is located in the Mission District of San Francisco, on the ground floor of the Sunshine School. The second floor, which is the Sunshine School, houses an alternative high school. The center offers a full day program, from 7:30 a.m. to 5:30 p.m., 5 days a week, for 72 children, 18 of whom have special needs.

This is mainstreaming at the very youngest age, 2 weeks at times. All of our families, those with both disabled and nondisabled children, could be considered high risk. Thirty of the seventy-two parents are teens who attend high schools. Two of those teens have disabled children, a double whammy. All of the families are low income and are either working, in training programs or going to school.

Of the 18 parents of disabled children who are presently enrolled, 14 have been able to continue working, continue their schooling, or return to the work force. Without this help, most of these parents would have had to resort to welfare assistance. I have submitted some written material documenting the value and the economic feasibility of early intervention.

The four remaining parents are essentially unemployable at the present time. One has a brand new baby. One is under outpatient treatment for schizophrenia, one is a recent Spanish-speaking immigrant, and the fourth parent is in a depressed state. The latter two parents are being helped to acquire skills and improve their mental outlook by volunteering in the center and receiving satisfaction from this work.

It is difficult to present statistics regarding the rate of children's continued mainstreaming after graduation. Two-thirds of our children are moderately to severely disabled. Here in California, we do mandate programs for children who are 3 years old and over but few programs are mainstreamed.

We talked earlier about the need for advocacy during the IEP process. If you have a good program for children under 3, that process can start very early. We are the advocates for the parents during the IEP process when their children first experience this very crucial transition into a school district program. They go from a very protective environment, either in hospitals or in an infant program, and are then faced with a segregated program in which their child is "different" and is not included in the ordinary mainstream of the schools. Sixty-seven percent of these children would not ordinarily go into a mainstream program, but what about those other 33 percent? These are the children that we expect and hope will be mainstreamed. A very recent wonderful success story at our center involved a child who came to us at 18 months old, who was barely sitting, and who had severe anomalies, Vater syndrome. Through very concentrated work and therapy with him and liaison with the medical community, at age 3, he received a scholarship to go into a Montessori school as an ordinary mainstreamed child. Many of his disabilities were resolved, and his parent, as she aptly put it, remained out of mental institutions. It is this kind of early intervention that is crucial for both child and family. It is this kind of intensive full day, 5-day program which could accomplish this result.

The children with special needs are completely integrated into our seven classrooms. The program was developed in 1975 to 1978, as a model under a Federal grant from HCEEP [Handicapped Childrens Early Education Program]. We have a transdisciplinary team of physical therapist nurse, speech therapist, and special education teacher as staff and consultants. These professionals work with both parents and teachers in the classrooms and in the child's home. The flexibility of the program adapts to the needs of families by recognizing that economic issues may take precedence over other needs and by giving families the respite which will allow them to deal with their child's disability more effectively.

We see some parents daily, some seek us out for counseling, advice and help, others may spend time only with their child's therapist. We serve many families who are maybe immigrants. Many of our families are Spanish-speaking only, because we are in the Mission District of the city and accessible to this population. Our special education consultant is herself disabled. She is blind and Spanish-speaking. These qualities lend credibility to our program and we are also able to serve families who need to relate to a person who knows and understands their culture.

Our funding comes from several sources and I would like to talk a little bit about our difficulties. We have had to fight very hard to be recognized as a truly therapeutic program. Mainstreamed day care is not yet differentiated from child care. We are partially funded under the regional center system, but the regional center usually approves and purchases only 2 days a week for program services since that is usually what the traditional program offers. The children from most of our families would not benefit from 2 days a week; they need to be in the center 5 days. The weekly cost of therapeutic day care is almost identical to that of the traditional infant program. The guidelines determined by funding agencies need to be broadened so that barrier to limitation or prevention of service delivery to these neediest families are not created and perpetuated.

Services for children who have diagnoses of developmental delays, cerebral palsy, or a neurological disorder are purchased by the Regional Center, but there are many other children who are severely disabled who do not come under those categories. We have a grant from a private foundation, the first grant of this type they have given for services outside of a medical institution, for children who are medically disabled. We have children who have leukemia, end stage renal disease and other medical disabilities. The program enables those children to live in a normal nonmedical environment on a day-to-day basis. We provide medical monitoring, liaison with the medical community, and we give assistance to our families in dealing with very confusing medical information. When your child is first diagnosed, you do not hear what the physicians are telling you; we help interpret and explain medical information. We also administer some medical treatments.

The obvious conclusion to my presentation is that we need more of this kind of program which serves the highest risk families.

Chairman MILLER. Thank you.

Florene?

[Prepared statement of Trudy Latzko follows:]

PREPARED STATEMENT OF TRUDY LATZKO, PROGRAM DIRECTOR OF THE DEVELOPMENTAL SERVICES DEPARTMENT OF FAMILY SERVICE AGENCY OF SAN FRANCISCO

Chairman Miller and Committee Members, I appreciate your giving me the opportunity to serve on this panel.

As Program Director of the Developmental Services Department of Family Service Agency of San Francisco, I have been asked to describe the services our Agency provides for young disabled children, ages 2 weeks to 3 years, and their families. But before I do that I would like to express my professional and personal opinion, based on 25 years of experience as a nurse and program administrator, that parents of disabled young children need to have program options available to them so that they can choose a program which best meets not only their child's needs but takes into consideration their family's needs as well.

Most programs for children under three years of age have traditionally been designed to offer assistance to families through home visit and/or center sessions during which parents observe and work with professionals in order to learn to implement demonstrated therapeutic activities with their child. These sessions usually last one to three hours and may take place one to three times a week. This type of program is ideal for families in which one parent does not work and he or she is able to carry out these suggestions at home.

The reality of life today, however, is that women *must* work, families may not be highly functioning in our society and although these infant programs may offer excellent services, they simply do not meet the needs of a large percentage of families.

Consider a few examples:

A fourteen year old mother whose child has a severe metabolic disorder, This young mother needs to attend school. Her family speaks only Spanish.

A family in which the father is periodically unemployed. The mother's job is essential to support three children, one of whom is severely disabled.

A single parent who drank heavily before she knew she was pregnant. She is receiving therapy for alcoholism and the guilt she feels toward her child who has Fetal Alcohol Syndrome.

None of these families would be able to benefit from a traditional program.

The Family Developmental Center is located in the Mission District of San Francisco on the ground floor of the Sunshine School. The second floor houses an alternative high school. The Center offers a full day program, five days a week to 72 children, 18 of whom have special needs.

All of our families could be considered "high risk". Thirty of the 72 parents are teens who attend high school, two of whom have disabled children. All of the families are low income and are either working, in training programs or attending school.

Of the eighteen parents presently enrolled, fourteen have been able to continue working, continue their schooling or return to the workforce. The four remaining parents are essentially unemployable at the present time: One has a brand new baby, one is under outpatient treatment for schizophrenia, one is a recent Spanish speaking immigrant and the fourth parent is in a depressed state. The latter two parents are being helped to acquire skills and improve their mental outlooks through receiving satisfaction from their volunteer work in the Center.

It is difficult to present statistics regarding the rate of the children's continued mainstreaming after graduation from our program. Sixty seven percent of our children are moderately to severely disabled: they would not be expected to remain in mainstreamed programs. The other 6 children are receiving the kind of therapy and help which we hope and expect will result in their continuing into regular preschool settings. We recently had a child who has severe multiple anomalies receive a scholarship into a Montessori preschool after being in the Family Developmental Center for 18 months.

The children with special needs are completely integrated into the seven nursery/classrooms. The program was developed between 1975 and 1978 as a model under a federal grant under the Handicapped Children's Early Education Program. A transdisciplinary team provides speech therapy, physical therapy, feeding consultation, behavior management and special education consultation. These consultants work with both parents and teachers. Parents are encouraged to spend as much time as they can in the nurseries. We see some parents daily—some seek us out for counseling, advice and help. Others may only spend time with their child's therapists. We serve many families who speak only Spanish and who may be recent immigrants; our special education consultant is both disabled herself (blind) and Spanish speaking.

Our funding comes from several sources. The children without special needs are funded through the Child Development Division of the California State Department of Education. Services for children who have diagnoses of developmental delay, cerebral palsy or a neurological disorder are purchased by our local Regional Center. We also have a grant from a private foundation to serve 7 children with medical disabilities, many of whom would not qualify for services from any other source. We provide medical monitoring, liaison with the medical community, assistance to families in dealing with confusing medical information and difficult medical issues and we administer some medical treatments.

The obvious conclusion to this presentation is that more programs of this type and scope are needed to serve this very needy population.

STATEMENT OF FLORENE M. POYADUE, PARENT AND EXECUTIVE DIRECTOR, PARENTS HELPING PARENTS, INC., SAN JOSE, CA

Ms. Poyadue. Yes. Thank you.

Thank you for inviting me. As Minnie Pearl would say, I am pleased to be here.

I would like to address several issues regarding parents, needs, and I will center my comments around behaviors and attitudes that start at the very beginning, in the hospital setting, for these families. And, also I would like to describe to you our unique and inexpensive programs that I think could be an answer, at least a large part of an answer, for some of the problems that we are talking about here today.

As executive director of a mutual self-help parent support group, I listen to many parents of disabled, chronic, or terminally ill children. I have concluded that the issues for the 1980's center around three main areas, ESP,-education, support, and professionals.

Taking these three in reverse order, because I do want to go all the way back to the hospital setting when the baby is born. Let me start with professional issues.

Trying to coordinate your child's care, and sometimes just encountering some professionals changes the challenging drama of raising a child with a handicap into a frustrating, agonizing nightmare. It takes some families months to recover from the negative attitude and approach with which some doctors disclose the diagnosis to new parents.

For instance, approximately 25 percent of physicians still recommend immediate institutionalization, although that has long since been proven not to be the method of choice.

Many are not aware of resources, services, and agencies to which they can and should refer families. When my child was born, they told me to take him home and love him. Thank God, I ran into a parent who said, "Florene, there is more to do than that. Let us get this kid into a program."

Professionals will often not tell you the ranges of the child's potential, but concentrate on the lowest possible range that the child's ability might meet. Many professionals will not listen to parents' concerns, acting as if the mom's brain exited the uterus with the baby.

Too many are hesitant, or are not willing to call in peer or parent support groups. They fail to use a comprehensive team approach and that has been mentioned here earlier. The linkages of the health care system and the educational system, the physicians and nurses and social workers in the hospital must begin to work with the school districts.

The day before yesterday, our parent support group put on a hospitalization and discharge planning symposium. It was the first countywide symposium on this issue. It is going to be the first of an annual symposium on the needs of special needs kids in Santa Clara County. We got all of these different groups together to work on this issue. There were doctors, nurses, social workers, principals, teachers, et cetera, and it was a parent support group that accomplished this.

We had a very exciting day from 8:30 in the morning till 5 in the evening. I was very pleased that one physician came up to me, very emotional, and said "I learned something. I came here. I thought I would just share, but I learned something, and I also had tears in my eyes twice;" and where do you get your funding? I said, "We do fund raisers. We are putting on one June 23." He said send me 50 tickets. I will sell them. So, not only did he get educated, but he got involved.

Besides the failure of many professionals to use the comprehensive team approach, there is a tremendous stress on these families from the many professionals who suddenly impact on them, and no one of these professionals totally coordinates the child's case.

Parents must become the child's case manager; making all final decisions. Who helps the parents with that? The parents are willing to do that, but we do need a resource and some help.

Many professionals fail to realize that taking care of a handicapped or chronically ill child means taking care of a family, not just that child. There is a failure to use the collaborative shared management approach that is mandated in Public Law 94-142. The parents are to be included and too often we find ourselves fighting for that inclusion. We talked a little bit earlier about having attorneys at meetings and parents trying to get a proper IEP process, and it seems to me the system is spending more money fighting the parents instead of giving them the rights they need. Then, we would not have to pay attorneys.

Sometimes, what they are calling an attorney in for is probably a $25 program cost. Instead of getting the child the program, they would rather fight the parents, and cause frustration. That is where a lot of the problem lies.

SUPPORT ISSUES

As far as support is concerned, parents need financial assistance. As has been said previously, government agencies are willing to spend $1,000 a day while a child is in an institution, with three shifts of nurses taking care of the child. Then the child is discharged home to one mom to do the same job 24 hours a day, 7 days a week.

Surely, a government agency that is caring enough to intervene at the time of birth, to ensure each child's right to life and proper care, does not intend to abandon that same child because he exchanged his hospital bed for a home bed.

Asking parents to sell their home and possessions until they become welfare patrons before offering help does not help the child either.

Parents need peer support. I cannot say that often enough. We have talked about many professionals who impact a family, and help. We do need that professional care. But, we also need each other. Parents need contact and information from other experienced parents.

I asked all of the agencies at the symposium the other day to please begin to include parents on their planning committees in hospitals and in other organizations. They are overlooking a vast wealth of information, experience, and knowledge when they do not include experienced parents.

A little example. An 11-year-old boy had a skateboarding accident. He is now multiply handicapped, and was about to be discharged from the hospital. The nurses, first of all, were very upset because the mom was in denial. She would not accept the fact that this child was in a coma, was not going to do better, and they said, Florene, what are we going to do with her. I said, well, right away, you are not going to try to change her attitude. She is where she should be, in denial. When your kid is skateboarding one minute, you cannot accept the fact the next minute, the next 6 weeks or the next 6 months, that he is not going to be doing anything but sitting there in a coma the rest of his life. Nature protects us by providing "denial" in the grief cycle.

Thank God, the mom persisted. And, thank God, they had the good sense to call Parents Helping Parents, and ask what can be done. We sent over an experienced parent who had taken care of such a child in his home. He talked with the new parent. The hospital allowed that experienced parent to also sit in on the discharge planning for the child. They said that the experienced parent was the most valuable person on that discharge planning team. The child is out of a coma now, and beginning to do well. That parent needed support from another parent; someone to say that it is OK to hang in there, even if "they" say your kid is not going to make it. Sometimes, "they" are wrong.

There are parent support groups in many communities. The problem here lies in getting professionals to understand the benefits of self-help or mutual help thoroughly enough so that they become committed to taking the responsibility to see that their patients or clients have access to this vital therapeutic mode.

Handing a flyer or a brochure to devastated parents; or worse, just posting one in the lobby, is not commitment enough. As a nurse, they nor I, and I am a nurse, would ever dream of handing a post-op patient a flyer on the benefits of coughing. We would insist that they do it, and we would call in experts, respiratory therapists, if we did not have time to do it.

The experts on recovering from the shock of the news and the experts on rearing a child with handicaps or illnesses are experienced parents. They should be called in.

Through contact with other parents, the family's isolation is broken, thus preventing child abuse and many of the other things that have been talked about here today. Parents are helped to maintain some similance of balance and sanity for themselves. But most importantly, the child is given the greatest chance for reaching her or his fullest potential.

A helped parent is truly a helped child. If Easter Seals gives a child a brace and mom and dad are too depressed to put it on, what good is that brace?

Parents Helping Parents gives to special needs kids the one thing they need most; we give them special parents. Special parents are not people who are dropped from heaven, or made by God and all these different things. Special parents are knowledgeable about the laws protecting their child. People who are well informed about their childs disability and ability. Parents who are assertive. Parents who are directed. Parents who are involved in child's care. Parents who are caring and competent, and advocating for their child's rights.

Our organization, Parents Helping Parents, tends to make that kind of a parent of a new parent when they come to us. We have a poignant, touching letter from a mom who wrote to PHP.

She said "PHP, thanks to your help and support, we brought Veronica home." She had been in an institution since birth.

We did not offer her any money, we just offered her enough support so that she felt she could bring the child home.

Educational issues. Last but not least. The issues around obtaining a free, appropriate and in the least restrictive environment education promised by Public Law 94-142 often becomes a constant war between parents and educational systems.

On the one side, the school staff is engaged in protecting their budgets, changing criteria for eligibility, and quoting quotas; while the parent is, first of all, getting over the trauma of their dashed expectations that the school would be working with them, helping them to get the best program for their child, instead of working against them.

An example, not more than 10 percent of student populations can be considered special needs. If so, we up the criteria. If you have more than 10 percent students, you have to up the criteria so that only 10 percent will fall in that range.

A child, at this time, because we have kept upping the criteria, must now show a 50-percent deficit before adapted physical education is begun. That means an 8-year-old must be functioning like a 4-year-old before he can get help.

By the time we intervene, remediation takes twice as long or has much less of a chance of helping and cost is probably doubled. Other problems include: (a) parents cannot get the program the child needs. (b) There is an inappropriate mix of ages in the classroom—6-year-olds with 12-year-olds. (c) The program plan for an 8-to-1 pupil/teacher ratio, when visited there were 16 handicapped kids to 1 teacher. (d) Kids being punished for symptoms. Example:

A mother was told if her child with Tourette's Syndrome, as you know, those kids will often jerk themselves or yell out. They cannot control it. And, the mother was told that if her child yelled out in class one more time, she would be punished for that. So, the kid is going to be punished for a symptom that she cannot control.

(e) Learning disabled children—We have not touched on that very much today. This is a large, large group. We just started a division in our organization called P.O.L.D. [Parents of Learning Disabled Children]. We had 20 parents 1 month, and in 2 months, we had 132, and we did not even advertise in the newspaper.

Learning disabled children and their problems are misunderstood, mislabeled, and they are misplaced. Parents must often convince the schools that something is wrong with their child, and that he does need assistance. (f) The IEP process, I will not go into it very much because many problems surround it and have been touched on by others here. Placements or assignments being made before assessment is done. I do not know how that can be, but parents complain about this.

Plans are completed before getting the parents' input is another problem in this area. They are not clearly written. A lot of educational jargon might be used that parents do not understand. Parents are intimidated, rather than consulted and trusted and respected. Sometimes they are written and not done. Just to name a few things, that I hear parents complaining about.

I see a parent support organization as one of the vital missing links that can be used to bridge the gap in solving many of these issues. Parent support groups need assistance to develop financial and technical assistance.

Thank God, we are now beginning to get some financial assistance from the Federal Government and through the TAPP Program, Technical Assistance to Parent Program. We are getting some technical assistance. That is a beginning, and we need more of it.

We perform an invaluable unique service. Our organization, Parents Helping Parents, to just tell you about a few of the things that we do: We have a Visiting Parent Program, where we match up an old parent with a new parent who has a child with the same disability; one who can speak their language, et cetera.

That old parent becomes a friend; breaks the isolation, gives the new parents emotional support and direction; and will help with the IEP. Sometimes we even have the old, or I should not say "old," people do not like that, the experienced parent, don a suit, take a briefcase, and go along with the new parent to the school. Perhaps the IEP team thinks this is an attorney, but is not, it is a parent. It is very effective, the new parent feels supported, and the school district is just a little less intimidating.

Family Rap or Guidance Sessions, which we call [FROGS]. Sometimes handicapped people are kind of looked at as ugly, but if you really get to know them, they are like that frog, they are a beautiful prince once you get to know them.

In the FROG sessions, we have counselling by peers and education by professionals. We have parent training. We train our parents in peer counselling skills so that we can give them assertiveness skills, communication skills, at the same time, we are preparing them to help each other.

We have information packets on disabilities in layman's language so they can understand it; also, AWS services, rights information. Our package started out being this thin, it is now this thick. We also put information in those packets about normal parenting so that the parents know they have a kid who is a child as well as a child with a handicap.

We have a quarterly newsletter full of education and inspiration and legislation. We have public and professional training, and that is one area that I feel is often remiss. We often talk about training parents. Professionals need training also. Like doctors need training in better ways of telling the parents about the diagnosis. They need training in what resources and things are in a community.

Parents Helping Parents has developed a program called Better Ways for Physicians, and we do go in and train. We have also written it up in a training manual so that it can be replicated around the country, and I am pleased to say that people are writing for it, and it is also in four foreign countries, Israel, Canada, Mexico, and Australia. They are using our model for training physicians. We also have a workshop for nurses, and they can get continuing education with it. It is called "When Baby Isn't All Right," where we train nurses in better ways.

We do things with educators. So, at our parent support group, we are doing a lot of things with and for parents, but half of our program is for professionals.

Chairman **Miller**. I am going to have to ask you to conclude the list. We are——

Ms. **Poyadue**. OK. Right. Will do. Real fast.

Siblings of disabled children need help, and we are planning programs for the siblings. Siblings, I think, are the gifts of handicapped children to the world. When you heard Ann talk about her daughter this morning, and some of you probably felt that that was a lot for a fourth grader to do. Siblings of handicapped kids are more mature than their peers; more tolerant of differences and a lot of other things.

So, siblings are a great asset that handicapped kids give to us. We are helping siblings with this program. We have a gift to newborn, to say that is a human being you have there. We do this to foster acceptance by the parents. We have school outreach programs, where we help a child with epilepsy to go in and talk to the class, to sensitize the other children to her needs and how they can help her and what it is all about.

We need funds like everybody else, but to give us \$150,000 to run our group is very cost effective, because if we help two families to keep their children out of institutions for just 1 year each, that would more than take care of the \$150,000 that it takes to run our budget. It costs \$60,000 to institutionalize one autistic child for just 1 year.

Right now, we have no help from anyone except the corporations and foundations in Santa Clara County, and the parents that support us.

Thank you.

[Prepared statement of Florene Poyadue follows:]

Prepared Statement of Florene M. Poyadue, RN MA (Parent) Executive Director, Parents Helping Parents, Inc.

As Executive Director of a mutual, self-help parent support group, I listen to many parents of disabled, chronic or terminally ill children. I have concluded that their issues for the 80's center around three (3) main areas—ESP—Education, Support, and Profesionals.

Taking these three in reverse order—Professional issues. Trying to coordinate child's care and sometimes, just encountering some professionals changes the challenging drama of raising a child with a handicap into a frustrating, agonizing nightmare.

It takes some families months to recover from the negative attitude and approach with which some doctors disclose the diagnosis to new parents.

25% still recommend immediate institutionalization, although that has long since been proven not be the method of choice.

Many are not aware of resources, services and agencies to which they can and should refer families.

Ranges of child's potential abilities are not discussed, most often only the lowest range is focused on.

Many won't listen to parents concerns—acting as if mom's brain exited her uterus with the birth of the baby.

Hesitant or not willing to call in peer, parent support group.

Failure to use comprehensive team approach—There is a tremendous stress from the many professionals who suddenly impact one family; no one of these professionals actually coordinates child's case—Parents must become the child's case manager, making all final decisions.

Failure to realize that taking care of a handicapped or chronically ill child means taking care of a whole family.

Failure to use collaborative, shared-management approach with parents.

Support—Parents need financial assistance. Government agencies are willing to pay \$700/day for Intensive Care Nursery bill, with three nurses changing shifts. But, the child is discharged home to one mom to do the same job 24 hours a day, 7 days a week. Surely a government that is caring enough to intervene at the time of birth to assure each child's right to life and proper care, does not intend to abandon that same child because he or she exchanged the hospital bed for one in the home. Asking parents to sell their homes, etc. and become welfare patrons before helping does not help the child.

Parents also need peer support, contact with and information from other experienced parents. There are parent support groups in many communities. The problem here lies in getting professionals to understand the benefits of self-help or mutual help thoroughly enough so that they become committed (emotionaly and intellectually bound to act) to taking the responsibility to see that their patients or clients have access to this vital therapeutic mode.

Handing a flyer or brochure to devastated parents (or worse, just posting one in the lobby) is not commitment enough. As a nurse, they, nor I would ever dream of handing a post-op patient a flyer on the benefits of coughing. We'd insist that they do it, or we would call in experts, Respiratory Therapists. The experts on recovering from the shock, of the news and on rearing a child with handicaps or illness are other, experienced parents.

Through contact with other parents, not only is isolation broken, and parents are helped to maintain some semblance of balance and sanity for themselves, but the child is given the greatest chance for reaching her or his fullest potential. A helped parent truly equals a helped child. If Easter Seals gives the child a brace and mom and dad are too depressed to put it on, what good does it do? When asked what Parents Helping Parents gives to special kids, I quickly reply, "We give special kids what they need most—special parents (knowledgeable, well-informed, assertive, directed, involved, caring, competent parents).

We have a poignant, touching letter from a mom who wrote "PHP, thanks to your help and support, we brought Veronica home!" (in institution since birth).

Education issues.—Last, not least, the issues around obtaining that free, appropriate, in the least restrictive environment education promised by PL 94-142 often becomes a constant or intermittent struggle, a war between parents and the educational system. On the one side, the school staff is engaged in protecting their budget, changing criteria for eligibility, quoting quotas, while the parent is first of all getting over the trauma of their dashed expectations that the school would be working with them, helping them to get the best program for that child.

Example: Not more than 10% of student population can be considered special needs, if so, up the criteria. Now, a child must show a 50% deficit before Adaptive Physical Education is begun. This means an 8 year old must be functioning like a 4 year old. By the time we intervene, remediation takes twice as long as or has much less of a chance of helping, and cost is probably doubled.

Other problems include:

—Parents can't get program child needs,

—Inappropriate age mix in classes (6 and 12 years old),

—Program planned for 8 to 1 pupil-teacher ratio, now has 16-1, and

—Kids being punished for symptoms

—Learning Disabled children and their problems are misunderstood, mislabeled and misplaced. Parents must often convince school that "something is wrong".

—IEP (Individual Education Plans) Many problems surround it: placement assigned before assessment done; plan completed before meeting and parent's input; not clearly written; educational jargon used that parent's don't understand; parents intimidated rather than consulted and trusted and respected; written, not done.

I see parent support organizations as the vital missing link that can be used to bridge the gap in solving many of these issues. Parent support groups need assistance to develop and financial assistance to stay afloat. We perform an invaluable, unique service.

Our organization Parents Helping Parents, Inc. tries to address the aformentioned issues by offering the following programs:

—Visiting Parents.—Matching old and new parents. This offers emotional support, information, direction, help with IEP.

—Family Rap or Guidance Sessions (Frogs).—Counseling by peers; education by professionals

—Parent Training.—In peer counseling skills, I&R usage; etc.

—Information Packets.—On disability, services, rights, etc.

—Newsletter.—Quarterly education and inspiration.

—Public and Professional Training.—Workshops and Symposiums for doctors, nurses, social workers and other professionals.

—Helping Professional Students Practicum.

—Siblings of Disabled Children.—Fun Days and Diaries.

—Booklets and Training Manuals.—(Communicating with Disabled and families; How to Start a Self Help Group; How to conduct professionals' training sessions; Peer Counsel-training manual.)

—Gift to Newborn Program.—Welcome to the human family.

—School Outreach.—Educate and sensitization of classmates; help special needs student self-disclose disability.

We need funds to start classes for parents in IEP, PL94-142; and to train parents as case managers.

Chairman. MILLER. Thank you. Thank you very much.

Ms. POYADUE. While I am passing this, I'll share with you a picture that shows the difference in two attitudes. Last year, he had a teacher that did not believe he could learn, etc. This year, and this is one year later, he has a teacher who does believe he can learn. You would not think it is the same kid. That is my little boy, Dean Archibald Poyadue. He has Down Syndrome. Some people look at this picture and say "Does he have Down Syndrome?" but when they look at this picture, they pretty much know he has Down Syndrome. If you want to take a look, and I think a lot of that difference is just an attitude of the professionals dealing with him.

STATEMENT OF MARTHA ZIEGLER, PARENT AND EXECUTIVE DIRECTOR, FEDERATION FOR CHILDREN WITH SPECIAL NEEDS, BOSTON, MA

Ms. ZIEGLER. It takes years of assertiveness training to be able to be lost on this panel today.

First of all, I do want to say it is a privilege for me to be appearing before this committee, whose reputation as an advocate on behalf of families and youth is well known on the east coast as well as California, and everywhere in between.

It is a privilege to be a participant in this panel of very moving and expert witnesses today, and, finally, it is also a privilege for me to be delivering testimony prepared by my colleague, Betsy Anderson, who, like Florene, is one of the leading parent advocates in this Nation, in the area of health issues for children with disabilities and children who are chronically ill.

Betsy would have been here herself today, but she had to fly back to Boston last night to attend the funeral of her closest friend, who was a very well known advocate in the State of Massachusetts.

Betsy herself is director of health services at the Federation for Children with Special Needs in Massachusetts. She is the parent of three children, the oldest of whom, her son Michael, is now 20 and was born with spina bifida.

Today, I want to describe some of the broad range areas of need for parents in meeting the health care needs of their children. I also want to touch on a few of the urgent issues that parents are experiencing and, finally, I want to tell you briefly about some of the activities and approaches that are being initiated in this area. I will not talk in detail about the final area because we have enclosed packets with sample material for the committee.

First, broadly, the expectations for children with disabling conditions have changed dramatically in recent years, and as a consequence of those changes in expectations, families need to be prepared for very different roles.

At the time Betsy's son Michael was born, the recommendation for withholding treatment was a common one. Early death was anticipated for babies born with spina bifida or several other disabilities. And, at best, his life was expected to be that of a severely compromised person, who would, of course, live in some kind of institution.

Expectations have changed so dramatically that, today, even those children with substantial disabilities, will live lives very similar to those of their nondisabled siblings and peers. Michael is a college student, living in his own apartment, up the freeway here—I forget which town in California, driving a car—essentially he is, managing his own life.

He had his first experience admitting himself to the hospital on his own 2 weeks ago. Yesterday, Betsy and I urged him to come deliver this testimony. He should be here instead of me, but he responded, "Is it not enough that I pick up my mother at the airport and drive her around? Do I have to do her work, too?"

Parents typically begin with very little knowledge of their child's disability or of the treatment or procedures being recommended. Yet, today, they usually become the primary care givers and decisionmakers. Families spend more time than anyone else with their children. They provide the usual day-to-day care, which, for children with medical complications, may include giving medications, handling seizures, giving injections, changing dressings, giving occupational and physical therapy, monitoring sophisticated special equipment, and many other tasks associated with the particular child's needs.

The decisions parents must make are necessarily wide-ranging and they must assume active roles in the many settings in which their child receives services. These include hospitals, clinics, schools, recreational settings, home. Furthermore, these services are provided by a wide variety of professional persons: nurses, doctors, therapists, school personnel, recreational specialists, for just some examples.

Parents are the link among all these specialists, and the only people who see the child in all these settings. And, over time, the parent must be prepared to provide the overall management to coordinate the effort of these many specialists and the needs of the child within the context of the family.

The coordination that all of these activities requires is immense, and, of course, these tasks must be performed within the context of a family, whose other members have varying needs of their own.

Parents, thus, need to be informed, active partners with professionals, to ensure the best management for the care of their children. There is an urgent need for a system similar to the one that we have in special education, that would provide parents with the information, training, guidance, and support that they need to perform this crucial role.

If you think about it, hospitals do not have anything even like a PTA. There is no structure or systematic way for parents to communicate and exchange information with health care professionals.

Second, the new role just described for families must be carried out with the understanding and support of health professionals. Collaboration is critical to developing an integrated approach to children's care. While a carefully designed structure exists, as I mentioned, in special education, we do not have that in health care settings.

Hospitals tend not to have the same sort of opportunities for discussion, among parents, patients, and staff, which are common, even informally, in schools and in social service settings.

Instead, families struggle with an unwieldy, fragmented health care delivery system. In order to involve parents in these health settings as active team members, preparation is necessary for professionals to help them overcome their customary ways of viewing parents and children as passive recipients of care.

While many professionals, of course, are receptive, and even encourage and initiate such activities, others have not had the necessary training themselves, and, sometimes, they are not aware of the challenges families face.

These are the two underlying issues which confront our families with children with special health problems need.

Now, third, I would like to list—just simply list some of the current pressing issues that such families face, and I will select one of these to discuss in a little bit of detail.

There are three large areas of need: The first is information. This includes information about the child's disability, related current medical issues, new medical information that becomes available, as time goes on. Information about the child's medical records. Information appropriate for the children themselves at various ages.

Financial information. Information specific to particular hospitals and clinics. Information concerning rights and entitlements. Parents need information on both short and long-term issues around their child's health problems.

The second large area is training. It is very clear that parents need training to perform this new role as case manager and as collaborator with health care professionals.

The third area of need is support. As Florene so eloquently indicated, parents need connections to other families of similar children. They need connections to organizations and groups concerned with problems similar to theirs, and they need to have input into health care policies and practices.

The fourth area is communication and collaboration with health care professionals. Parents need an opportunity to participate as an equal member of the health care team in a way similar to the equal role that parents play in special education. They need an understanding of the needs and views of specific health care providers and access to information which can provide understanding of the larger issues faced by health care systems.

There are many immediate and pressing needs for families who have children with health care needs and with chronic illnesses and medical disabilities. But, one of the most pressing is the area of health insurance, and I would like to go into that one in just a bit more detail.

Chairman MILLER. Let me just say that we are going to have to be out of here at 1 o'clock. So, we want to leave a little bit of time for questioning.

Ms. ZIEGLER. OK. There is a problem of access. There is often discrimination against disabled people for commercial health insurance. The information about what is covered, and to what extent, is not readily understandable.

There is a whole system of exclusions. Our children have exactly those illnesses and those disabilities, that require the precise procedures that are most likely to be excluded in health insurance plans. Health insurance plans frequently have lifetime limitations.

You may look at a policy that says $250,000 as a lifetime limit; that may look terrific, but if you have a child requiring surgery every few months or every few years, that amount can disappear fast. We know of a family in which the policy will not cover the same procedures and the same care if it is delivered at home instead of in a hospital.

I just want to make three summary statements as Martha Ziegler, and these are that the earlier stories you heard on the earlier panel are not unique to California. The Supreme Court now is attempting to deal with the zoning problem. If the *Clayburgh* decision comes down the wrong way, we will be appealing to you to enact legislation that will enable 94–142 graduates to remain in the community.

Finally, two more items. Florene referred to a Federal grant program for training parents in many of the areas discussed today. As one might expect, the administration has suggested a cut in that program. We will look to you for help in that area.

And, finally, we hope that you will sign on to support the community and Family Living Amendments when they are introduced in the House. That piece of legislation in the new version contains a long laundry list that would be of great value in solving many of the problems that you heard today.

Thank you.

[Prepared statement of Betsy Anderson follows:]

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS,
Boston, MA, April 19, 1985.

Select Committee on Childen, Youth and Families,
Anahiem, California.

Good morning. My name is Betsy Anderson and I am the parent of three children. My oldest son, Michael, who is nearly twenty, was born with multiple, handicapping conditions which have necessitated continuous involvement with health care systems and which were the reason I first became involved in the issues I want to speak to you about today.

I work at the Federation for Children with Special Needs which is a coalition of parent-run organizations in Massachusetts concerned with a variety of disabling conditions. The Federation also coordinates a national network of 62 parent centers across the United States.

For the past four years, I have directed a project which presents parent perspectives on caring for children with disabilities and chronic illnesses to health professionals, policy makers, as well as to other parents.

Today I want to describe some of the broad areas of need with some of the implications for parents. I also want to touch on some of the current, urgent issues to give you a sense of what parents are experiencing. Finally, I want to tell you briefly about some of the activities and approaches being initiated in my area. (If I have misjudged the time, all of this is in the written material I have given you.)

First, broadly, the expectations for children with disabling conditions has changed dramatically and as a consequence, families need to be prepared for very different roles. At the time my son was born, the recommendation for no treatment was a common one—early death was anticipated and at best, his life was expected to be that of a severely compromised individual in an institutional setting.

Now the expectation is that children, even with substantial disabilities, will live lives very similar to those of their nondisabled siblings and peers. Michael is a student, living in his own apartment, driving a car . . . essentially managing his own life. In fact, two weeks ago he had his first experience admitting himself to the hospital on his own.

Parents typically begin with very little knowledge of their child's disability or of the treatment or procedures being recommended, yet today they usually become the primary care-givers and decision-makers. Families spend more time than anyone else with their children. They provide the usual day-to-day care, which for children with special needs may include: giving medications, handling seizures, giving injections, changing dressings, giving occupational and/or physical therapy, monitoring special equipment and any of the other tasks associated with their own child's particular special needs.

The decisions parents must make are necessarily wide-ranging and they must assume active roles in the many settings in which a child receives services. Care may be given in a number of different settings—hospital, outpatient clinic, school, recreational setting or home, and by a wide variety of individuals—nurses, doctors, therapists, school personnel, recreation specialists and parents. Parents are the link among all these specialists and the only people who see the child in all these settings. And over time, the parents must be prepared to provide the overall management to coordinate the efforts of these many specialists and the needs of the child within the context of the family.

The coordination that all of these activities requires is immense. (And, of course, these tasks must be performed within the context of a family whose other members have varying needs of their own!) This responsibility goes well beyond what is expected of even the most dedicated social workers, pediatricians or other helpers.

Parents need to be informed, active partners with professionals to insure the best management for the care of their children and a system is needed to provide information, training, guidance and support.

Secondly, the new roles previously described for families must be carried out with the understanding and support of health professionals. Collaboration and communication are critical to developing an integrated approach to children's care.

While a carefully designed structure exists within special education to ensure and protect the participation of parents of handicapped children, no such structure exists within the medical and health care arena. Thus, each new parent is left to search out information, support, and a definition of the parental role.

Hospitals tend not to have the same sort of opportunities for discussion among parents, patients and staff which are so common in education and other social service settings. This lack means that there is no way for people in different roles to get to know each other, no way to know that concerns are shared and no way to discuss how cooperation toward common goals might proceed.

Instead, families struggle with an unwieldy, fragmented health care delivery system. In order to involve parents in these health settings as active team members, preparation is necessary for professionals to help them overcome "customary" ways of viewing parents and children as passive recipients of care. While many are receptive and even encourage and initiate such activities, others have not had the necessary training themselves, and sometimes are not aware of the issues families face.

These are the two underlying issues which affect families of children with special health needs. The appendix contains listings of more specific need.

APPENDIX

INFORMATION

The following is a listing of some of the kinds of information which families need access to in order to carry out their roles in an informed way.

A. *Child's disability or diagnosis.* This is one of the first things parents request and most say they still do not get enough (or sometimes even any). Needed is easy access to a variety of levels of information from short overview brochures intended for parents to current, technical medical material.

B. *Related current medical issues* as a particular child's situation indicates. For any child these will vary but some examples might be information on spinal fusions for a child with spina bifida, articles on seizures for a child with cerebral palsy, etc.

C. New information that becomes available about the disability or new interpretations of old information (especially important for families of older children).

D. *Child's medical records.* Families and older children should be encouraged to read and review the medical records from time to time. While it may be helpful for staff to be available to respond to questions, such assistance should not be a stipulation for such viewing.

E. *Information appropriate for children.* A range of material in varying formats, with pictures, diagrams, etc. This is one way to begin to prepare children for their own future roles.

F. *Non-medical resource information.* For example, community services, special education entitlements, day care, respite care, etc., the kinds of information that would give people important links to the larger world.

G. *Financial information.* (Before an actual need arises) hospital/physician billing—costs and procedures, understanding of insurance coverage, public assistance, Hill-Burton and any other sources of funds.

H. *Information specific to the hospital:*

1. Hospital structure and functioning information that would help families understand the organization and the ways they can proceed.

2. Hospital policies, particularly those that affect families.

I. Information concerning rights and entitlements in health care.

J. Finally, parents need information on both short and long term issues. Short term issues should reflect situations as parents and children will be likely to experience them. Material written by other parents is particularly important.

TRAINING

A related and increasingly important area is that of training. Parents are most often the people who carry out day to day care at home, supervise other caregivers, and help children who are learning to manage their own care.

Needed

A. Preparation and instruction to meet our children's particular needs. In many cases this is appropriately "individualized" and "on-the-job" but in other cases this could occur prior to the child's actual needs. This might happen as children are being seen on an out-patient basis or as part of in-patient care. (Since discharge occurs so quickly now it would in fact be helpful if anticipated needs could be prepared for ahead of time.) Each condition or situation has its own special procedures but examples might be: cast care, lifting and turning, suctioning, giving injections, to name a few. Much training material, already available for other health professionals, could be utilized with appropriate adaptations. Families also need the chance to practice these skills, whether with their own children or in other ways.

B. Families also need to develop skills that are more general in nature in such areas as decision-making, planning, management, supervision and advocacy.

C. Information about instructional programs being offered within hospital or health setting—courses, conferences, etc. There also should be provision for parents and older children to attend seminars, in-service trainings, etc. being sponsored by the health center. (Since space and cost are often real considerations, a certain number of slots for consumers could be reserved.)

D. It is also important for parents, children, and adults with disabilities to present information and perspectives to health care staff on a regular basis.

SUPPORT

Families need to be able to mobilize their already existing support systems of extended family and freinds and in addition, most will want the special support which can be offered by other parents who have had similar experiences.

A. Connections to other individual families whose children have the same or similar disabilities.

B. Connections to organizations and groups concerned with their own child's disability or problem (national if not local).

C. Health care policies and practices which encourage the presence and active participation of families in the care of their children. Policies should include grandparents, siblings, friends and others important to the child and family.

COMMUNICATION AND COLLABORATION

Families need opportunities for discussion and collaboration with professionals. These should be available on both an individual level as well as on system and policy-making levels.

A. The opportunity to participate as an equal member of the health care team, similar to that provided under P.L. 94-142, with the chance to present observations, opinions, hopes, wishes, and the chance to hear the same from others. The same opportunity is needed for older children.

B. An understanding of the needs and views of specific health care providers—and the chance to work with them to develop solutions.

C. Access to information which can provide understanding of the larger issues faced by health care systems and the opportunity to contribute whether in terms of money, time, effort, ideas, etc.

EXAMPLES OF CURRENT ISSUES AFFECTING FAMILIES

1. While most children with handicapping conditions have received clear benefits from P.L. 94-142, the same cannot be said for children with chronic illnesses. Although the language in the definitions appears to include them, the reality is that in most school systems children with asthma, juvenile rheumatoid arthritis, cystic fibrosis, and other health impairments are inadequately served. Families and health providers across the country are beginning to ask for services to meet the needs of this population of children.

2. There are major issues occurring in the area of homecare for children with serious medical needs, for example, children who depend upon either special equipment or specially trained caregivers, (children on ventilators, on home IV or parenteral nutrition systems, those on home kidney dialysis and those with tracheostomies and gastrostomies).

Many families are learning the necessary skills in order to take their children home from hospitals. Among the issues: discharge planning, including training and preparation for families; funding mechanisms to support children at home; adequate preparation and availability of community support personnel, especially nurses.

Health insurance

3. The first problem, one you are probably familiar with, is access. Although it is popular for health insurance companies to use the term "cafeteria style" to describe the available packages, individual families have no such choice. We are bound primarily by the plan selected by our employer—if we are lucky enough to have one.

In addition, the information about what is covered, and to what extent, is not readily understandable by even reasonably curious individuals. Of course, the fact is, most people sign up for coverage without any knowledge that they may have special needs to use it later on and in any case would probably wish to avoid serious consideration of future disability.

Second, exclusions. Our children have exactly the illnesses and disabilities and are likely to require the procedures most apt to be excluded.

Thirdly, related to the previous issue of homecare, families who sincerely want to take their children with serious medical needs home from the hospital are very apt to find that a) their insurance policy contains no provisions for homecare coverage, even though they may be fully covered while in the hospital, and b) that even when medical staff present diagnostic and prognostic reports and detailed plans for homecare requirements, many companies refuse to specify what they will cover—and to indeed disallow after the fact. The stress on families that this causes is really unconscionable.

Fourth, while many groups, not the least of which is the government, study ways to shorten expensive hospital stays and the possible applicability of DRG's for pediatrics, some insurance companies are already deciding the number of days they will pay for coverage for certain procedures. This has been done with no notification to policyholders and without advice or input from organized medical groups.

Chairman **MILLER**. Thank you very much.

Congressman Lehman?

Mr. **LEHMAN**. Just a question. Ms. Poyadue, I mentioned the hospice program for the elderly. You mentioned about terminally ill as well as the handicapped. I do know that disabled children are sometimes also terminally ill. There are hospice programs for terminally ill children as well as those for the elderly terminally ill. I would like for you to provide that for me, especially if you know of any in and around Washington or in and around South Florida, where I can visit.

And, I just want to mention, there is a book out just within the last few years, I have not read it, written by a person named Stanley Elkins, a well known writer. I do not know the name of the book. It is one of the books that is what you call nonfiction novels, which is half-true and half-novel, but it is a story about a man that lives in the United States and takes 12 terminally ill children to Disneyland, right where we are now. He describes the experiences and the wisdom he got from these children and the conditions that they had. I am trying to get the book. If I do find it, I will try to share it with some of you, probably.

Thank you.

Chairman MILLER. Congressman Evans?

Mr. EVANS. Mr. Chairman, just a quick question or two.

I take it that the Federation for Children with Special Needs Program is a State program.

Ms. ZIEGLER. It is a statewide program, but we also have a contract with the Federal Government to deliver technical assistance to similar coalitions of parents across the country. That is called the TAPP project.

Mr. EVANS. All right. And, I know Trudy and Florene are also trying to do things in that regard.

Now, what is the response of the medical society and the AMA's as a nationwide organization?

Ms. ZIEGLER. We have some proposals pending that we hope will enable us to impact at the national level. However, Betsy Anderson, and some of our colleagues in Boston have facilitated inclusion of parents on some advisory committees in hospitals in the Boston area. I do not mean to say that this is unique to Boston, but this is what I know about.

For instance, when Boston Children's Hospital decided to expand their physical plant, they included parents on the planning committee and parents had input and changes were made in the design of the new addition to meet the needs of families.

That is one little example.

Ms. POYADUE. Could I give another one?

Mr. EVANS. Sure.

Ms. POYADUE. Another little example is that I had a call from Stanford University Hospital just yesterday, after some of their members attended our symposium, and they are planning a new children's hospital there, and want me to act as a consultant to form a parent advisory board for the new hospital. Parents and professionals working together can change things; parent support groups can make that link between parents and professionals.

Mr. EVANS. All right.

Ms. ZIEGLER. Betsy also has a team of parents and professionals who actually give seminars in medical school settings in the Boston area.

Ms. LATZKO. We found it was difficult to reach doctors, that they did not recognize, they had a lot of resistance about even dealing with the problem, and the only way we did that is through actual in-services at their own hospitals. We did that with a local Kaiser Hospital in San Francisco, and whereas we have not gotten one referral in the previous 3 years, we now have a very good relationship with those doctors at Kaiser, and we have been receiving referrals.

So, that is one way that people really have to know that they can deal with it by flyers or telephone calls or even—I do not even think that they would deal with it through the AMA. They have to deal very personally with these doctors, so they can see their own patients being helped.

Mr. **Evans**. Well, my question is, though, what is happening in San Francisco, Florene, I do not——

Ms. **Poyadue**. San Jose.

Mr. **Evans**. San Jose, and in Boston. Does it happen in Rock Island, IL, or——

Ms. **Ziegler**. We are trying.

Mr. **Evans**. I am sure there are professionals here also that are trying to do it in their own locality, and it is probably an agenda item of the Council for Exceptional Children, but does the AMA give this the same level of attention? That is one of our big concerns. How do we get them involved at a national level, so that it is not a piecemeal local concern done on a local basis.

Ms. **Ziegler**. What parents have done for years in education and every other area, you know, we circle the wagons. We come in from every direction. One of the things that Betsy succeeded in accomplishing this spring was cooperating with the regional office of Maternal and Child Health in the New England region, and sponsoring a day-long conference for parents and professionals who are dealing with families of children who are on ventilators or respirators. You are probably familiar with the problems with Medicaid and a whole lot of things that interfere with getting those children out of hospitals and into their homes and developing quality care within the home; that conference was attended by, I believe, 140 health care professionals, including pediatricians, orthopedic specialists, nurses, social workers, from throughout the New England region.

It was a very important first step. It was cosponsored by the federation, which is a parent organization, and the regional office of maternal and child health. That is another way of——

Ms. **Poyadue**. I would like to add that California is holding its first parent professional collaboration conference May 8, 9, and 10, and we have included the health professionals in that.

Mr. **Evans**. Thank you, Mr. Chairman.

Chairman **Miller**. Thank you.

Steve, how many attendants have you had?

Mr. **Brees**. I have no idea. Literally. I—let me see. I have lived independently since 1972. It is now 1985. I—my guesstimate would be somewhere between 30 and 40.

Chairman **Miller**. And, that is not unusual?

Mr. **Brees**. That is not unusual. Sometimes people will work with me for 3 or 4 months only. But, what often happens is that, you know, I will put an ad in the paper and the nonprofessional person will want to work for a week and then leave.

Chairman **Miller**. That is the biggest barrier to stable care?

Mr. **Brees**. To what?

Chairman **Miller**. To stable attendant care. Can you achieve it?

Mr. **Brees**. The biggest barrier for me. Well, for me, personally, I have experience training people. So, training is not the problem for me, the problem for me is money.

Chairman **Miller**. Money?

Mr. **Brees**. The problem for me is—again, to make enough working in order to pay people to get me to work.

Chairman **Miller**. I want to thank all the members of this panel.

In my 10 years, these two panels have delivered and described about as good a cross section of the problems that families encounter that I can recall. I think that it provides a wonderful opportunity to start thinking about how we go the rest of the way after 94-142, now that we have extended partial services to families and families now understand the difference in life with and without services. We should learn from the many cost trade-offs that can be accomplished, such as in your program, Florene.

I would like to know what percentage of those parents would have turned to out of home placement for their children had they not had some kind of support network? That is the kind of evidence we put together before writing the foster care bill. Maybe it is the kind of evidence we ought to start thinking about again, so that we can use resources in the most efficient manner, whether for attendant care or day care. We have got to do this kind of analysis with respect to the handicapped community.

Thank you very much for your time. We have had a great experience here this morning. I want to thank the Council for Exceptional Children for helping us. For those of you who stayed the whole boat, a special thanks.

The record will remain open. I am sure there are some parents and some educators and professionals and others out here in other fields who would like to contribute to this body of knowledge.

We would invite you to do so. We will hold the record open until May 3, and, again, thank you very much.

With that, the committee stands adjourned.

[Whereupon, at 1:05 p.m., the committee was adjourned.]

[Material submitted for inclusion in the record follows:]

PREPARED STATEMENT OF CATHY COOK CHILDERS, PARENT OF A CHILD WITH DISABILITIES, NORTH CAROLINA

I appreciate this opportunity to share information regarding the stresses and challenges facing parents of children with disabilities.

Prenatal oxygen deprivation resulted in my son's profound mental retardation, cerebral palsy, uncontrollable seizure disorder and blindness. Christopher, now three years old, is a very valued, loved member of our family.

A most difficult experience for parents is receiving the news that their awaited child has a serious disability. This situation is even more unbearable when presented by medical personnel who lack training and sensitivity. While we were fortunate in having a pediatrician who informed us of Christopher's disabilities and abilities in a caring, supportive manner, I have met many parents who were devastated by this experience.

Medical professionals need a greater awareness of the impact of a child's disability upon the family. A program at the University of North Carolina—Chapel Hill Medical School, coordinated by Claire Larch, requires pediatric residents to have hands-on experiences with children with disabilities and to role play situations such as informing parents of their child's disability. Mandatory training of a comparable nature for all medical professionals would enable them to better understand parent needs.

In addition to the emotional stress, new parents suffer frustration and a feeling of overwhelming inadequacy due to a lack of vital information. I sought resources and information from the very beginning, but did not learn of many available services and organizations until months later. Other parents have related that years passed before they received appropriate information or services.

Effective, expedient sharing of information could be improved by the development of a standard packet, readily available to medical professionals for prompt distribution to parents. This packet should include fact sheets about specific disabilities, lists of resource organizations and available services, and simple explanations of the disabled child's rights.

I am personally involved with The Listening Parent Program, a service which links new parents to experienced and trained parents of children with disabilities in order to provide emotional support and practical information. New parents quickly establish rapport with another parent who says "I know what you're going through" and means it. Volunteer Listening Parents also aid new parents in seeking services and training opportunities.

Additional support services desperately needed by families of young children with disabilities include early intervention and respite care programs. An in-home intervention service, initiated when Christopher was two months old, provided therapists to assess his needs, develop a stimulation and physical therapy program, and train us to implement the program. The Respite Care Program offered our family relief from the constant 24-hour a day responsibilities of Christopher's care. Without the assistance of respite providers, we would have been unable to leave our home to perform even the most basic household errands.

For the past year Christopher has resided at Piedmont Residential Development Center (PRDC), an intermediate care facility for ten non-ambulatory children with severe disabilities. Despite our knowledge that this facility could better provide the close medical supervision and therapeutic services that Christopher needed, the decision to seek placement was indeed difficult. PRDC is a unique facility offering the children total community involvement in everything from scouts to church services to athletic teams, while allowing them to reside within twenty miles of their parents' homes. Christopher can receive the medical care that his physical disabilities require, and yet experience as normal a childhood as possible including daily parental contact.

Community-based residences such as PRDC can in no way be rivaled by larger institutional settings apart from the child's family and community. Though our placement decision was difficult, it can not compare with the agony of parents who have no residential alternative but the mammoth facility hours away. I strongly urge your support of the Community and Family Living Amendments which will enable other children to remain near their parents while receiving needed services in the most normalized setting.

As I prepare for Christopher's immediate future, I face a fight for his basic right to receive an education in the least restrictive environment. Despite a decade's existence of Public Law 94-142 and Section 504 of the Rehabilitation Act, our local school system maintains a totally segregated school for children with moderate, severe or profound mental retardation. All children with disabilities have the right to an appropriate education with their non-disabled peers and the right to related services to enable them to benefit from this education, such as physical therapy, transportation or counseling. Yet parents across the nation face insurmountable obstacles daily in accessing and understanding these rights for their children.

The assurance of these basic rights will only follow government and citizen involvement. Compliance with PL 94-142 and Section 504 must be more strictly monitored and enforced. Parent training regarding these laws and advocacy techniques enable parents to more effectively seek the maximum educational opportunities. Also, courts should reinstate school system reimbursement of attorney fees to parents with meritorious court cases.

In conclusion, I feel that the following can diminish or alleviate much of the stress faced by families of young children with disabilities:

(1) Improved medical professional training.
(2) Timely availability of information.
(3) Linkage to other parents.
(4) Early intervention services.
(5) Respite Care.
(6) Community-based residential facilities.
(7) Passage of the Community and Family Living Amendments.
(8) Enforcement of PL 94-142, Section 503 and 504.

I and other parents in North Carolina stand ready to assist your committee in any manner in achieving our mutual goals.

Again, thank you for allowing me the opportunity to express these concerns and for your attention to these issues.

TEAM OF ADVOCATES
FOR SPECIAL KIDS,
Orange, CA, April 26, 1985.

Congressman GEORGE MILLER,
Select Committee on Children, Youth and Families,
385 House Office Building Annex 2, Washington, DC.

DEAR CONGRESSMAN MILLER: Thank you for your letter dated April 15th asking for written comments regarding "Families with Disabled Children." We are encountering a drastic decrease in the provision of services to families who are trying to keep their children at home. Although facts substantiate this is the most cost effective method, in reality the service systems which are suppose to be providing support services to enable this concept, are not providing the needed support.

Regional Center of Orange County's major portion of their budget is spent in the areas of our home placement and related services. Respite services for in home clients have been neglected and money has been reduced in this category, in relation to clients served in home. To my dismay, we encounter this agency's priority is providing out of home placement and related services. In home clients are not a priority.

California Childrens Services has been reducing the amount and time of physical and occupational therapy services provided to in home clients for the past several years. This is placing a tremendous burden on families who are trying to secure these services privately. Therapy services are now $40/hour in our area. Many people cannot afford the premiums on insurance policies for a pre existing disability.

AB 3632 was recently passed in California "mandating" local Mental Health Agencies to provide necessary psychological services to children in public education programs. This bill also "mandates" CCS to provide all children with an evaluation and provision of physical and occupational therapy services. In reality, this bill will allow for less children to be served. Prior to passage of AB 3632, education was responsible to vendor out services they did not provide. Each of these agencies have stated throughout the years, "We do not have necessary funding".

Please be advised necessary support services must be provided in order for parents to maintain their disabled children at home. The rate of out of home placement in Orange County has increased drastically (statistics provided by Department of Developmental Services). I believe this is directly related to the lack of necessary support services being provided by public agencies. I also feel another look should be taken at the financial responsibility portion of parents for utilization of public agencies. The rearing of a disabled child is much more costly than that of a normal child.

Thank you for this opportunity to address this important issue. If I can be of any further assistance please let me know.

Sincerely,

CATHERINE LAMARCHE, *TASK Director.*

STOCKTON, CA, *May 1, 1985.*

Hon. GEORGE MILLER,
2422 Rayburn House Office Building,
Washington, DC.

DEAR CONGRESSMAN MILLER: It was a unique and warming experience to hear you address the Council of Exceptional Children plenary session in Anaheim last month. I enjoyed hearing a congressman rail for family values and warming to the intellect to know there are counter forces in this country to the squeeze, cut, and trim mentality for all domestic programs as evidenced by the present administration. There must be a counter force to those who would write blank checks to General Dynamics and General Electric charging for household pets to take airplane jaunts with their owners.

I am writing because I hope to have this added as testimony to the Select Committee on Children, Youth, and Families of the United States House of Representatives. I bring a unique perspective to your deliberations. I am minimally involved with Cerebral Palsy. I worked for ten years at Central Valley Regional Center for the Developmentally Disabled in Visalia, CA. I am presently a doctoral student in Counseling Psychology at the University of the Pacific in Stockton, CA.

My testimony to you comes from someone who has felt the sting of discrimination at work for not being able to motorically stay on top of paper shuffling responsibilities. I speak to you as someone with an awkward gait who knows what it is to feel the sting of peer rejection, and I know what a patchwork, or mine field of social agencies exist for frantic parents to keep "special children" at home. This to maintain a semblance of mainstreamed activities while input from different professional groups about your "special child" has a parent going five different directions at the same time. I have been a professional giving advice to many sets of distressed parents about not likable alternatives in those circumstances.

Rather than continue with these generalties and establishing my credentials, permit me to get specific about the testimony of many of the individuals making up the two panels: As a professional, I need to warn you about the objectivity of parents' testimony. My heart and gut rend and wrench for some of the circumstances of the parents, but depending on the severity of the handicapping condition, many times agencies serving a spastic, quadriplegic, severely retarded child with a heart anomaly have had no other choice in the community other than state hospitalization because of the special care needed by that child.

In Mrs. Beverly Bertaina's case, the issue needs to be addressed as to how many services can exist in Sebastopol, CA, Tie Siding, WY, or in Cooperstown, N.Y. when a child needs so much servicing. Doesn't it make more sense to have small facilities, (bed capacities of six to ten) in Santa Rosa, CA, Laramie, WY, or/and Albany, N.Y. That way school and support personnel are not tripping over each other making 25 mile, 40 mile, or 100 mile trips to service someone. The parents, school districts, and other responsible agencies can make accommodations each giving somewhat to meet the child's needs.

In terms of Ms. Mary Short's issues, it seems that financial responsibilities of that absent parent were of a permanent eventuality. Possibly something could be done with the Internal Revenue Service tax code to permit credits for parents whose children need day care, or specialized services. This might at least assuage some of the sting for Ms. Short.

The testimony of Prof. Ann Turnbull was indicative of the giving or attractiveness of living in a town of 30,000 like Lawrence, KA, but how do you mandate that in Chicago or Atlanta, where the next door neighbor may not care what you do or how you do it.

I found myself ponderously engaged in the situation of Stephen Brees, where society gives mixed messages to the physically handicapped. The overriding one I feel, have felt, is that handicapped should not compete for jobs with "able bodied, John Wayne sterotypes of the human condition." All apologies to the deceased, but the appearance of health, stealth, stamina, and youth are very operative in this country. So, how attractive as a policy maker, do you make it for the Stephen Brees' of the country? It is not a rhetorical question. The support system, financial and emotional, is not in place for him. Do you want it to be? Does it make sense financially for it be in place? Maybe, the thing to do for Stephen is to permit him to struggle for his place as a professional. If he doesn't make it economically, he should not be penalized with his loss of Supplemental Security Income and his Medi-Caid should cover for his emotional adventure and cost for putting himself on the line in trying to work.

Lastly, in speaking to the issues developed by Mrs. Florene Poyadue, I say bravo for organizing parents in the community, state, and country to address her vested concern. But, to the extent parents can be objective in speaking to the concerns of their "special children", don't necessarily assume all of the heat applied equals light. The handicapped don't need false prophets. For those communities who set up programs for their handicapped, provide them grants and start-up moneys for programs. But, what will happen to the needs of her constituents when Florene burns out, retires, or the movement reaches a plateau? When the superstructure of the organization, set up to take care of the constituency meets the needs of an organization, who is left to meet the needs of the disenfranchized?

I guess my message is, organizations have a purpose and CEC certainly has provided noble service. How many splinters from parent groups end up speaking to the needs of the children or do they serve more the needs of the parents?

This has perhaps, become more of a rambling discourse, than a response to the issues raised by the presented testimony. Nevertheless, I believe it sufficiently focused to assist you in deliberations, before writing any bills to eventuate from this hearing.

Thank you for considering this input.

Sincerely yours,

William G. Palmer.

GARDEN GROVE, CA, *April 23, 1985.*

Re: written input for hearings.

Hon. GEORGE MILLER,
Chairman, Select Committee on Children, Youth, and Families, House Office Building Annex No. 2, Washington, DC.

DEAR MR. MILLER: I am the parent of two daughters and two sons who range in age from 27 years to 10 years, our youngest being a son who has severe brain damage resulting from cytomegalovirus causing profound mental retardation and multiple physical disabilities. Robert is nonverbal, nonambulatory and requires total care in all areas, including self-help skills.

Robert is small for his chronological age which makes it possible for us to continue to care for him in our family home. As he continues to grow and become more difficult for us to physically handle, it would be beneficial if we could depend on having available to us, meaning his father and myself, some in-home support services such as a person who could assist with some of the lifting at bathtime, and also give us an occasional break from the bathroom routine as well as the 3-times-a-day feeding responsibility. A person who could come in for, perhaps, four hours a day, five days a week from 4:00 P.M. to 8:00 P.M. A break from the daily home program of physical therapy would be helpful. This type of assistance, funded by or resources developed by Regional Center of Orange County, would make it possible for Robert to remain in our home for many more years at much less cost than if we found it necessary to place him in an alternate living situation.

Respite comes in many forms other than having a person come into a home to allow the parents to leave the home, or taking the disabled child to a careprovider for a certain number of hours. Respite could mean having available many facilities throughout the County which could provide integrated meaningful day care which would allow both parents to work if so desired.

Respite could mean having available through the County integrated and appropriate extended day care facilities which, again, would allow some other parent to work full time jobs and be taxpayers.

Respite could mean the availability of multi-level social/recreational activity programs for those persons looking for activities in which to participate in evenings and/or on week-ends, thus allowing more variety and normalization in the lives of handicapable persons and also giving the parents some "free" time.

There needs to be a variety of options of types of respite available to each family inasmuch as each family's needs are individual, as are the needs of each atypical person. Because a child does not have severe medical needs is not to say the stresses of caring for that child are any less. Disabilities come in many variations and varieties and so the needs of the family for a "break" are myriad, thus making it critical that there is a great deal of flexibility in the types and amounts of "respite" available in the community.

In some instances, if only a certain amount of respite is to be allowed to a family, this needs to be of a cumulative nature as some families can readily handle the day-to-day scheduling of activities and care but do feel the need for a total break from the responsibility for several days at a time. In the working world one is given a vacation from work responsibilities for a number of days in each calendar year to allow the employee to rest, recuperate and rejuvenate, and the same theory is plausible when considering the ongoing responsibility of parents caring for an atypical person.

Since caring for a disabled person is a 24-hour a day, 7-day a week commitment, it is, of necessity, mandatory to build some "for me" time into the person's life to minimize the "burn-out" factor.

As you are well aware, I am sure, the cost of maintaining a special child at home is about one-sixth the cost of maintaining that same child in a State-operated facility. The quality of life can, in no way, be as great in a care facility as it is at home where the daily activities of a family are more normal and there is greater opportunity for interaction with typical peers as well as persons of varying ages.

Thank you for receiving my input to your Blue Ribbon Committee.

Sincerely,

CAROLYN V. DOWNES.

SERVING ASIAN AND HISPANIC PARENTS:
CALIFORNIA INITIATIVES

Sam Ch[illegible], Ph.D.

University Affiliated Program
Childrens Hospital of Los Angeles

Paper presented as part of a panel on "Reaching Special Parent Populations" at the National Conference on Parent/Professional Partnerships, Washington, D.C., August 1984.

Introduction

Within the State of California, ethnic "minorities" currently comprise well over one third of the population and by 1990 will collectively represent a majority of the State's citizens (1). Thousands of new immigrants, particularly Asians and Hispanics, have contributed to this dramatic growth. Moreover, these recent immigrants are characterized by predominantly non- or limited-English speaking families with young children, including significant numbers of children with handicapping conditions.

Such population trends and characteristics have exacerbated the long-standing problem of multiple barriers which inhibit access to needed services and information. Language is predictably one of the most significant barriers. The lack of language-appropriate informational materials for non-English speaking individuals is compounded by the lack of bilingual, bicultural personnel among provider agencies. Another major barrier is the lack of culturally responsive service models which address relevant cultural orientations and behaviors affecting service utilization. Non-English speaking individuals are also in great need of specific information concerning resources, rights, and responsibilities; such information is often inaccessible because of earlier noted language barriers as well as inadequate outreach methods employed by provider agencies (2).

The barriers identified above have obviously contributed to the underrepresentation of Asian and Hispanic clients within an array of programs providing services to handicapped individuals and their families Thus, corresponding priority efforts to address cultural/linguistic barriers have been generated among the major State agencies serving special needs populations. The California State Council on Developmental Disabilities, for example, has designated "Services to Ethnic/Cultural Minorities" as one of its major planning and program development priority areas. Attention to ethnic minority concerns is also reflected in the Comprehensive System of Personnel Development (CSPD) implemented by the California State Department of Education (as required by PL 94-142 regulations). Among the "critical areas" designated in relation to priority pre-service and in-service training needs are "limited-English-speaking and non-English-speaking assessment and instruction" and "bilingual/multicultural special education" (3).

The "critical" nature of such concerns if obvious given the fact that well over 400,000 (or more than 10%) of the approximately four million students in California's public school system are considered "limited English proficient" (LEP) (4). Thus, among the nearly 360,000 children (birth to 21 years) utilizing special education services are a significant number of LEP students (5). Furthermore, there is evidence to indicate that additional numbers of handicapped non- or limited-English speaking children are either not participating or may be misplaced in various special education programs (particulatly those for the specific learning disabled, speech impaired, and mentally retarded) as a result of underidentification and misdiagnosis (6).

Among the previously described service barriers, the lack of qualified bilingual, bicultural personnel is particularly evident in the special education system. In fact, the acute shortage of credentialed bilingual teachers and other school personnel has reinforced the significance of original PL 94-142 mandates dictating parent involvement in the process of planning, implementing, and evaluating the child's education at home, at school, and in the community. Moreover, the recent PL 98-199 amendments support meaningful involvement through the provision of appropriate training and information to parents of handicapped children.

While including provisions for the training and sensitization of school personnel in relation to cultural/linguistic factors and special populations, the California CSPD further specifies the State legislation which calls for coordinated efforts in the delivery of ongoing personnel development programs to educational personnel, volunteers and parents. Corresponding information dissemination and technical assistance activities include: disseminating state, local, regional, and nationally recognized projects; distributing in-service training opportunities to educational and service agencies involved with handicapped children; sharing trainers and training materials among school districts and regions; conducting special training; developing training materials for statewide use; training of trainers; and linkage to other resources(3

Information and training programs for ethnic minority parents have thus been viewed as an essential means of promoting access to needed services as well as increased parent involvement in the development of policy and programs for children with handicapping conditions.

The critical need for corresponding culturally/linguistically appropriparent training models and materials has resulted in the establishment of federal and state supported special projects within California during the past four years. These projects have evolved in a systematically coordinated and sequential manner through statewide planning efforts and ongoing reciprocal support networks consisting of key agencies and organisations. The manner in which such model projects have been developed and their respective findings and products thus merit national recognition.

Minority Outreach Project

Protection and Advocacy, Inc. (PAI) was established in 1978 and designated to advocate for and protect the rights of developmentally disabled Californians. PAI services include provision of information, referral, training/technical assistance, and legal research and representation. In 1980, PAI was awarded a demonstration grant from the Office of Human Development Services for a pilot project to provide outreach services to ethnic minority developmentally disabled persons in the greater Los Angeles area. The resulting "Minority Outreach Project" was initially directed toward comprehensive outreach activities targeting the Korean population. Corresponding strategies and methods which were developed later served as outreach models for other Asian ethnic communities in Los Angeles as well as selected urban populations throughout the State. Project efforts then focused on identifying consumer needs and service barriers and means of enhancing the availability of relevant resources. Training was subsequently provided for both consumers and service providers in order to promote knowledge of legal rights and responsibilities and to improve consumer self-advocacy skills. Outreach and training activities were complemented by direct advocacy services rendered to individual clients.

The Minority Outreach Project received continuation funding from the Administration on Developmental Disabilities through December, 1983. Project target groups were expanded to include Hispanics and Vietnamese residing in Los Angeles County. Since its inception, the project has provided training for approximately 800 developmentally disabled persons and their families. Corresponding written materials have been developed and extensively used in these training activities as well as disseminated at the local, state, and national levels; among such materials is a training manual entitled "Service Rights and Entitlement Programs Affecting Developmentally Disabled Californians" which has been translated into Spanish, Korean, and Vietnamese.

PAI has maintained a commitment to continue providing specialized advocacy services to Asian and Hispanic communities. The original Minority Outreach Project has since been "institutionalized" through integration of project objectives into PAI's three-year plan and the hiring of project staff as permanent members of the organization. Moreover, PAI has succeeded in obtaining additional funding from the Los Angeles County Developmental Disabilities Area Board to support continued training of local Asian, Hispanic, as well as Black populations. PAI is also the recipient of a recent Department of Education, OSERS grant award which will support a two-year "training-of-trainers" project to be described later.

Asian and Hispanic Parent Education/Training Project

Since its establishment in 1966, the University Affiliated Program (UAP) at Childrens Hospital of Los Angeles has continued to function as a major community-based interdisciplinary training program, characterized by a primary emphasis on prevention, detection, early intervention, and provision of exemplary care to children with handicapping conditions and their families. Throughout the past ten years, selected UAP staff had pioneered the development of special parent education programs for various Asian populations and served in an advisory capacity to the PAI Minority Outreach Project. UAP staff then designed a model of comprehensive parent education for Asian and Hispanic families with young developmentally disabled children. The resulting "Asian and Hispanic Parent Education/Training (PET) Project" was initiated in October, 1983 through a one-year Program Development Fund grant award from the California Department of Developmental Services.

As the first statewide program of its kind, the PET Project has targeted non- and limited-English speaking Chinese parents (in the San Francisco and East Bay areas) and Korean and Spanish-speaking parents (in the Los Angeles area) to form distinct ethnic parent groups. Primary participants in the program are parents of developmentally disabled children ranging in age from birth to five years; however, parents of older children (6-12 years) have also been served at selected sites. Once recruited into the program, parent participants are each interviewed by bilingual/bicultural training coordinators.

The parents' individual needs are assessed in relation to information concerning the child's specific handicapping condition(s), methods of promoting the child's growth and development, parenting skills, and relevant community resources. Corresponding ten-week parent education programs are then developed and conducted in the parents' respective native languages. For each ethnic parent group, these programs include supplementary written materials in appropriate languages and culturally relevant educational formats designed to involve parents as active participants as well as train selected parents in the implementation of similar parent education programs.

Approximately 80 parents will have participated in the PET program by the end of the second ten-week training series to be completed in September at each site. Among these participants are the "parent facilitators" who have assisted the training coordinators in developing and implementing each session. The parent facilitator role is derived from the "Connections" model of parent training which was originally developed and field tested for English-speaking parents served through the San Diego Unified School District (7). The PET Project parent facilitators have each experienced a mutually rewarding and productive relationship with the professional training coordinators. While acquiring increasingly sophisticated group facilitation and leadership skills, the parent facilitators have been instrumental in stimulating participant discussion, sustaining parent interest, motivating follow-through on various recommendations, and creating group cohesiveness which engenders collective problem-solving, personalized sharing of experiences/conflicts, and emotional support. Moreover, the parent facilitators have demonstrated initiative in providing guidance and support for parents who "graduated" from the initial training series and who have independently decided to continue meeting on a regular basis. While developing organizational structures and plans for securing resources needed to maintain their educational activities, the original parent participants have, in turn, joined the second-series parent groups for selected sessions in order to share expertise, experiences, and provide additional support to the new participants.

Evaluation of individual participants outcomes has yielded similarly positive findings. Significant emotional, attitudinal, educational, and behavioral changes were reported and/or observed among nearly all of the participants. While acquiring improved personal coping, parenting, and advocacy skills, many participants succeeded in overcoming varying levels of stigma, shame, and isolation which they have previously experienced as parents of disabled children.

In evaluating the program, participants have consistently presented positive feedback in relation to both curriculum format and content. They have generally found the information received to be relevant and practical in meeting their needs. More specific participant input has been incorporated in the refinement of project training methodologies and materials for each ethnic group. The final, detailed project report will be completed in November, 1984. A training guide and curriculum materials will also be published for statewide dissemination at that time.

The project will further offer continued support and technical assistance to parents and selected bilingual/bicultural providers who have participated in the program and received training as parent trainers. Such training will have been conducted throughout the program and supplemented by an intensive two-day training experience provided through "Project TOT".

Project TOT

In 1978, a committee of parents and professionals from Los Angeles County Regional Centers for the Developmentally Disabled sponsored the first "Fiesta Educativa", an educational conference for Hispanic, Spanish-speaking parents of developmentally disabled children. The Fiesta subsequently evolved into an increasingly popular annual event and, in 1980, served as the foundation for the incorporation of the State Hispanic Council on Developmental Disabilities - an organization referred to throughout Hispanic communities as the "Concilio". The Concilio now serves as a statewide network of autonomous Hispanic parent advocacy groups dedicated to education and training activities designed to stimulate leadership, professionalism, and participation in the developmental disabilities service delivery system.

In continuing to sponsor the Fiesta Educativa, the Concilio presented a training-of-trainers model for Hispanic parents during the nationally recognized "Fiesta Educativa '82". This model served as the prototype for the proposed Project TOT (Training-of-Trainers) which was funded by the Organization of Area Boards in California for the period of November, 1983 through September, 1984. Project

TOT was designed to establish local training-of-trainers programs in six distinct geographic communities with high concentrations of Hispanics and selected Asian ethnic populations.

Each local TOT program is initially directed toward the identification and recruitment of a team consisting of primary and secondary consumers as well as providers of developmental services. These team members then receive group training in community resource identification, accessing the service delivery system, advocacy issues, networking, and group organization techniques. Upon completion of the initial team training, each team member is then expected to begin training other small groups of parents and consumer advocates in their home communities.

Project TOT has received considerable technical assistance and consultative support from the Special Education Resource Network of the Personnel Development Unit (Office of Special Education, California State Department of Education) in addition to support from other state as well as federal agencies, regional centers for the developmentally disabled, local area boards, public schools, and numerous programs serving developmentally disabled children and their families. The enlistment and coordination of such support as well as the formation of advisory committees in each community served, illustrates the Concilio's and project staff's significant capability in the area of systems access, resource utilization, and interagency networking. However, termination of project funding in September, 1984 will require individual trainers and participating agencies to demonstrate initiative in training other parents and consumer advocates. The lack of ongoing project support and systematic coordination of such efforts may contribute to varying levels of successful follow through and possible fragmentation or isolation among original team members. The newly developed "Multicultural Training-of-Trainers Project" was designed, in part, to reduce such problems by means of formally establishing and maintaining parent-professional partnerships in the implementation of a two-year statewide training-of-trainers program.

Multicultural Training-of-Trainers Project

The Multicultural Training-of-Trainers (MTOT) Project represents the culmination of several years of endeavor which has contributed to the development of collective expertise and specialized resources by Protection and Advocacy, the University Affiliated Program, and the

State Hispanic Council. The previously described special projects have enabled PAI, UAP, and the Concilio to establish mechanisms for pooling resources and systematic planning aimed toward building continuity among the various training efforts which target ethnic minority populations.

PAI served as the applicant for a federal grant through the Department of Education, Office of Special Education and Rehabilitative Services in response to the announcement of funds for new projects under the "Training Personnel for the Education of the Handicapped Program: Trainers of Volunteers, Including Parents" (authorized by PL 94-142, as amended by PL 98-199). The corresponding proposal to implement the "Multicultural Training-of-Trainers Project" was approved for funding and has since been initiated as of July, 1984.

The primary goal of this two-year project is to refine and implement culturally and linguistically appropriate education/training programs for underserved Asian, Black and Hispanic parents which will enable them to participate more effectively with professionals in meeting the educational needs of their handicapped children. During the first year of the project, PAI in primary collaboration with UAP and the Concilio, will establish training-of-trainers programs for non- or limited-English speaking Asian (Chinese, Korean) and Hispanic parents in communities within the San Francisco/East Bay and Los Angeles areas. These programs are designed to provide teams of parent and service-provider representatives with group organization and leadership training as well as education in a curriculum which will assist parents in: acquiring information about their child's specific handicapping condition, improving parenting skills, securing needed services, understanding legal rights and responsibilities, participating in decision-making processes, and developing self-advocacy skills. These parent-provider teams will subsequently serve as parent trainers who will organize, develop, and conduct related parent training programs in their respective communities and special education service settings. The local programs will incorporate previously developed written materials in various languages and culturally appropriate educational formats designed to involve parents as active participants. Project staff will provide continued support and technical assistance to the parent trainers and further facilitate the establishment of local and statewide parent communication, information dissemination, resource sharing, specialized training, and advocacy networks. During the second project year, these training and resource development methodologies will be extended to selected Black populations in Los Angeles as well as Indochinese communities in Orange and San Diego counties. Throughout each of the above endeavors, project staff will be guided by a governing committee on which a majority are parents of handicapped children and youth who represent various parent groups and coalitions within the State; committee members will also include appropriate agency representatives and professionals in the fields of special education and related services.

Conclusion

Despite their history and relative success, the California initiatives have only begun to address the needs of selected ethnic minority populations. Short-term demonstration projects have served to focus attention on these populations and to generate a collective momentum among participating agencies and organizations as well as coalition building among ethnic minority groups - particularly Asians and Hispanics with distinct language needs. However, expanded and sustained commitment of resources to effective outreach, training, and service models must occur among major institutions mandated to serve handicapped children and their families.

In the meantime, ethnic minority parents and community advocates should be supported in their efforts to develop formal/informal support networks and organizations. Moreover, opportunities for linkages with other major parent groups are necessary. Ultimately, the goals of "parent involvement", "parent power" and "parent/professional partnerships" will emerge as either less threatening or more than idealistic, but poorly operationalized legal mandates. A constructive, dynamic process of communication and collaboration among the diverse individuals who parent and serve handicapped children is challenging, yet well worth struggling for.

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MULTICULTURAL TRAINING-OF-TRAINERS PROJECT

MTOT

A Special Project of:
PROTECTION AND ADVOCACY, INC. [illegible] Capitol Avenue, Suite [illegible] Sacramento, CA [illegible] [illegible]

SITES:
UNIVERSITY AFFILIATED PROGRAM Childrens Hospital of Los Angeles P.O. Box [illegible] Los Angeles, CA [illegible] [illegible]
CENTRO DE NIÑOS Y PADRES CSULA, Dept. of Special Ed. [illegible] State University Drive Los Angeles, CA [illegible] [illegible]
ASIAN COMMUNITY MENTAL HEALTH SERVICES [illegible] Street, Suite [illegible] Oakland, CA [illegible] [illegible]
CHINATOWN CHILD DEVELOPMENT CENTER [illegible] Kearny Street San Francisco, CA [illegible] [illegible]

GOAL

The Multicultural Training-of-Trainers (MTOT) Project is funded by the U.S. Department of Education and administered through Protection and Advocacy, Inc. The primary goal of the MTOT Project is to provide training and information to ethnic minority parents of handicapped children to enable them to participate more effectively with professionals in meeting the educational needs of their children.

PROJECT FOCUS

MTOT is specifically directed toward the establishment of culturally and linguistically appropriate training-of-trainers programs for selected Asian, Black, and Hispanic parent populations in the San Francisco-East Bay and Southern California areas. These programs are designed to provide teams of parent and service-provider representatives with group organization and leadership training as well as information which will assist parents to:

(a) better understand the nature and needs of their child's handicapping conditions;

(b) provide follow-up support for their child's educational programs;

(c) communicate more effectively with related professionals and service providers;

(d) participate in educational decision-making processes;

(e) obtain information about available programs, services, and resources and their relative appropriateness; and

(f) understand relevant legal rights and responsibilities corresponding to provisions for the education of handicapped children.

Upon completing preliminary training, MTOT parent-provider teams will subsequently serve as parent trainers who will organize, develop, and conduct parent training programs in their respective communities and agency settings.

EXPECTATIONS

Each participating agency is expected to designate a staff member who will serve as a member of the parent-provider team. In this capacity, the agency representative will be required to attend an initial three-day training program and subsequent half-day follow-up training sessions (one per month) for a six-month period. The provider team member and/or appropriate agency staff should also be available to provide limited (up to one hour per week) administrative consultation and assistance to the parent team member as they develop monthly parent training workshops.

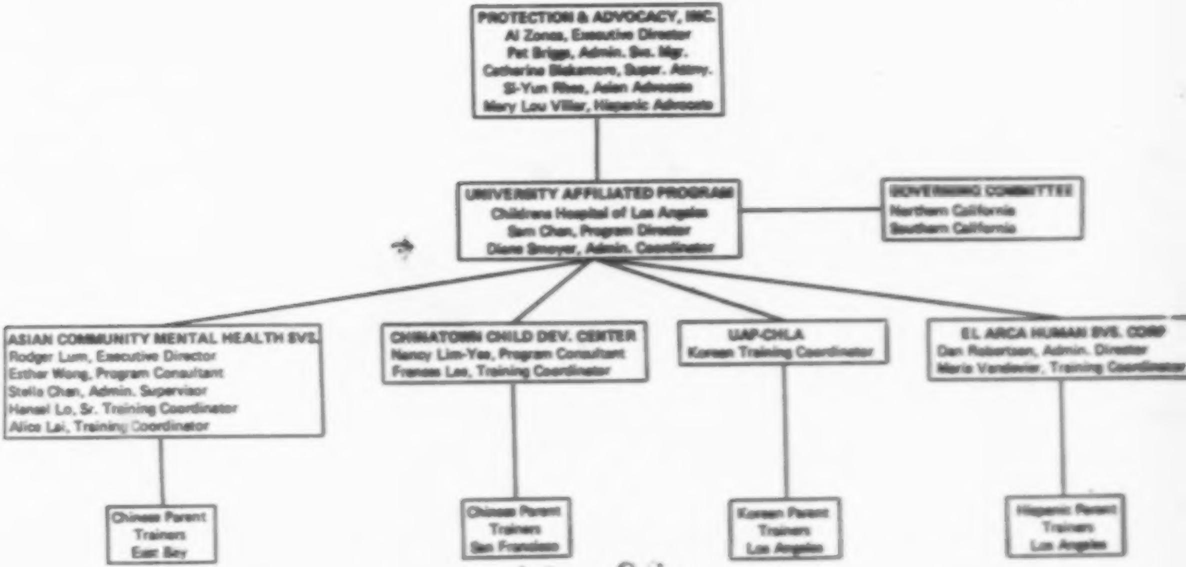
BENEFITS

MTOT will enable parents and providers to engage in mutually beneficial collaborative training activities. Participating agencies, in particular, will benefit from:

- Improved staff-parent communication and cooperation
- Enhanced staff leadership training skills
- Opportunities to better understand and address the needs of limited or non-English speaking ethnic minority families
- Increased information exchange, resource sharing, and networking with professionals and agencies having specialty expertise and bilingual/bicultural service capability

MULTICULTURAL TRAINING-OF-TRAINERS PROJECT*

1984 - 85


PROTECTION & ADVOCACY, INC.
Al Zonca, Executive Director
Pat Briggs, Admin. Svc. Mgr.
Catherine Blakemore, Super. Attny.
Si-Yun Rhee, Asian Advocate
Mary Lou Villar, Hispanic Advocate
UNIVERSITY AFFILIATED PROGRAM
Childrens Hospital of Los Angeles
Sam Chan, Program Director
Diane Smoyer, Admin. Coordinator
GOVERNING COMMITTEE
Northern California
Southern California
ASIAN COMMUNITY MENTAL HEALTH SVS.
Rodger Lum, Executive Director
Esther Wong, Program Consultant
Stella Chan, Admin. Supervisor
Hansel Lo, Sr. Training Coordinator
Alice Lai, Training Coordinator
CHINATOWN CHILD DEV. CENTER
Nancy Lim-Yee, Program Consultant
Frances Lee, Training Coordinator
UAP-CHLA
Korean Training Coordinator
EL ARCA HUMAN SVS. CORP
Dan Robertson, Admin. Director
Maria Vandevier, Training Coordinator
Chinese Parent
Trainers
East Bay
Chinese Parent
Trainers
San Francisco
Korean Parent
Trainers
Los Angeles
Hispanic Parent
Trainers
Los Angeles

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* Funding Source: U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS)
CFDA: 84.029P (Training Personnel for the Education of the Handicapped)

PREPARED STATEMENT OF KAY LAMBERT, ADVOCACY, INC., AUSTIN, TX

Thank you for the invitation to discuss with your Committee stresses facing families with handicapped children. The issues you are examining are important to us and we face them every day. Advocacy, Incorporated provides a variety of services both for people with disabilities and their families. We are a non-profit corporation, created in response to Federal legislation, to protect and advocate for the legal rights of Texans with disabilities.

Though we serve all ages and handle a variety of problems, the majority of persons who come to us for help are families of school-age children who are having problems with their child's education. To respond to this need, we have a separately funded parent training program that trains parents statewide to be more effective advocates for their disabled child. It is this perspective, from several thousand requests for help, that we bring to your Committee.

As you can imagine, parenting a child with a disability is stressful in itself. We see parents experience a great deal of additional stress because of having to fight with their local school district just to get services to which they are legally entitled. Ten years and numerous court cases after the passage of PL 94-142, disabled children are still being denied many services specified in the law. Parents with older children will tell us of years of battling with local school officials. Even parents who are finally victorious feel worn-down by the process. A word we hear frequently from them is "tired."

Parents who want to be active participants in their child's programming still often find their input unwelcome. They tell us of preparing for an IEP meeting and taking in a wealth of information and ideas about their child, only to be told they are "only parents" and not educators and to see their suggestions ignored. In a practice required by our state education agency, there is actually a "vote" taken at the IEP meeting on whether what the school proposes is appropriate. Parents have only one vote. Even if both parents attend, they still have only one vote. Even if the student is there, the family gets only one vote. But each representative of the school has a vote. And we are often told by school personnel that they are ordered before the IEP meeting to vote with the school person chairing the IEP meeting. You can imagine how frustrating that is for a parent and how hard it is to convince a parent it is worth even going to an IEP meeting when the deck is so clearly stacked against them before they begin.

In Texas, we are noticing an unmistakable trend toward re-segregation of persons with handicaps, even the re-opening of segregated campuses. Our state as a whole is experiencing a financial crunch as a result of declining oil and gas revenues. Funds for education, as for all other services, are being reduced. Unfortunately, the resegregation of handicapped students onto one campus is seen by some administrators as a way to save money. An increasing number of parents are calling us for help in fighting this pure discrimination which seeks to repeal the very basis of PL 94-142.

We see a refusal by schools to individualize services. Some youth, with only a few years of public school eligibility remaining, could make great strides toward independence if the program concentrated on their specific needs. But schools will not individually tailor a program, as PL 94-142 requires, and precious time slips away with youth in predetermined programs irrelevant to their future.

In Texas there is still little support for summer programming. Schools simply say they cannot afford it. You can imagine the frustration of a parent who knows how far their handicapped child could go if only the program continued to build month after month, but instead they see their child slip back with skills lost during a three-month gap in service. Similarly frustrating, Texas has a few early childhood programs, which make an enormous difference in the life of handicapped infants. These services stop when the child turns 3 and Congress intended for PL 94-142 to pick up at that point. But in Texas, the state education agency keeps PL 94-142 from being available at age 3 unless the child was 3 on September 1 of the current school year. Literally thousands of children get an invaluable head start then stagnate for up to 12 months at the age of 3 waiting for services to start again.

Texas is growing in population and we see terribly frustrated parents move in from other states where their children were making progress and find the local school unable to provide a program for their child. Instructional personnel often simply claim that they do not know how to teach certain skills to certain types of children. The comprehensive system of personnel development ordered by Congress so that promising educational practices would be acquired and disseminated to the local level cannot be found in our state. How frustrating to know from experience that your child can be taught effectively in one state, but not in another.

The understandable reaction of many parents facing services that are less than they know their child needs is to offer to help and ask to be trained in what they can do at home to supplement the school program. In our experience, most of these requests are refused by schools.

Some parents who know services can be better, and will not settle for inadequate local efforts, send their children away from home to programs that they know will make a difference. Yet we see the terrible stress that puts the family under when the "price" for an effective program is to separate parents and child. Often parents cannot afford these private programs for long and then face the stress of economic hardship or of bringing their child back to the inadequate public program and watching the child regress.

Parents of older children are extremely concerned about the lack of transitional services from school into community. In fact, quality community programs are scarce and poorly funded. Texas still has an amazing 9,000 persons in state "schools" for the retarded. This includes 2,341 school-age children and youth. Parents who have worked hard to make PL 94-142 work for their child often find themselves the parents of a 22-year old with no place to go. Worse, some schools try to discharge handicapped students at age 18 and tell parents they have to find services elsewhere. In fact, transitional and other services often require the involvement of agencies in addition to the education agency; yet our state education agency still refuses to negotiate the interagency agreement mandated in PL 94-142 and parents have to go on their own, agency by agency, trying to piece together appropriate services. Fearing that the future after school age may offer nothing, and that you will be alone looking for services, is very stressful and discouraging to a parent of even a very young child currently in a quality program.

In summary, we do not see the partnership between parent and school that Congress intended. We see families of disabled children still having to fight for services that Congress has said they are entitled to. We see them burning out trying to constantly monitor those services that they do get. We see parents who receive a little training and support make significant gains for their children; but we would rather see more school districts willingly providing services and the state education agency aggressively pursuing those who don't. We see parents heartbroken because their child is not getting enough programming to make a difference. We see even those parents who get a strong education program developed for their child afraid that when he grows up the community in which he has been trained to live will have no services or will even pass zoning laws to keep him out. We still see state "schools" for the retarded totally segregated with no contact with the nonhandicapped.

We know the solutions are not easy, but Congress' entry into this area 10 years ago has given us laws we can work with. We hope this information and perspective will be useful to you as you make your recommendations.

Prepared Statement of Elaine Hirsch, Chief, Disabled Persons Advocacy Division, Office of the Illinois Attorney General Neil F. Hartigan

Mr. Chairman, members of the Committee: On behalf of Illinois Attorney General Neil F. Hartigan, I appreciate the opportunity to offer some responses to the topic of today's hearing. Two years ago the General Assembly of the State of Illinois charged the office of Attorney General with the responsibility of providing advocacy services to disabled citizens of Illinois. To implement this responsibility, Mr. Hartigan established a Disabled Persons Advocacy Division. The Division is the only one of its kind to raise the issue of disability rights to the status of a full-fledged division in any Attorney General's office.

Advising the Divison are a Consumers Task Force comprised of 40 persons who are recognized experts in their fields of disability and a Lawyers Advisory Council comprised of 40 attorneys who have recognized expertise in one or more areas of disability law. The advisory group members each belong to one of the following subcommittees:

—Accessibility, Transportation and Voters Rights
—Education
—Employment and Vocational Rights
—Health, Mental Health and Insurance Benefits
—Housing, Zoning and Deinstitutionalization
—Legislative and Regulatory Development, Legal Services for the Poor and Conflicts of Interest.

Issues for the 1980's for families with disabled children are many and diverse. In the area of education, we have seen great progress due primarily to the passage of the Education for All Handicapped Children's Act (PL 94-142). Nevertheless, some problematic areas continue to exist. Of great importance is preparing the disabled student who is leaving school for other endeavors. There are few programs for the profoundly disabled student who is not ready for an activity or sheltered work program. In addition to the idleness and lack of purpose this imposes on the student, additional burdens are placed on the family when they are responsible for 24 hour per day, seven days a week care of their child. In addition to day programs for these young adults, other forms of respite care need to be made available to families who wish to maintain their children in their homes rather than in an institution.

I think you can appreciate how your own life would be affected if you could not take a vacation or even go out for an evening because there is no suitable care available for your child.

Preparing for work, whether in a sheltered environment or the open labor market needs to begin at a much earlier age.

In addition to better curriculum, institutions who should and could provide services with some modifications in their delivery of services, must be required to do so. Parents must be aware of these options and brought into the process at the junior and senior high school level. Let me give you an example, one parent asked her local school district about enrolling her child in the area vocational center. She was told the area vocational center does not have programs that are suitable for her child. When she asked the area vocational center about the lack of programs, she was told they haven't developed them because the districts have not referred any disabled students.

With the variety of needs and abilities of students who are disabled, parents are put on a merry-go-round which may or may not stop at the right service providing agency.

It is quite common for many parents of disabled students to be left on their own to find the proper program for their child when they leave the public school special education program.

As students approach the age when they leave school, parents are faced with another series of problems. Housing in the community is extremely limited. Knowledge of guardianship laws and whether guardianship is appropriate for their child is another area of concern. Health insurance becomes extremely difficult or impossible to obtain. Employment discrimination still exists at a disgustingly high level as exhibited by the percent number of disabled adults who are unemployed. Obtaining public benefits which might rightfully belong to an individual can become a nightmare. The Illinois State Bar Association in a public service program stated that persons applying for Social Security disability benefits can expect, as routine procedure, to have their initial application and their request for reconsideration denied. They then must request a hearing to be conducted by an administrative law judge.

Such a system denies persons who may have legitimately been eligible for benefits from receiving them because they assume that after being denied twice there is no point in requesting the hearing. For persons who do request a hearing, their chances of being successful increase substantially if they are represented by a trained paralegal or an attorney. Persons who do not know this often find themselves unprepared for the hearing and ultimately are denied benefits.

Finally, we must remember that the problems confronting families with disabled children often extend beyond the time when the child reaches the age of 18 or 21. There are many elderly parents of middle-aged children whose needs and problems we have barely touched upon but who we cannot forget as we plan for the future.

Attorney General Hartigan appreciates the initiative taken by this Committee in addressing the issues of families with disabled children and offers his support to your efforts.

PREPARED STATEMENT OF JACK HAILEY, EXECUTIVE SECRETARY, CHILD DEVELOPMENT PROGRAMS ADVISORY COMMITTEE, SACRAMENTO, CA

The current status of child care services for disabled children requires action. The Child Development Programs Advisory Committee has reviewed both the need for child care and the current level of service. Few families with disabled children have child care resources which allow both parents or a single parent to work full time; few have access to respite care.

To mitigate these needs and to increase child care services to exceptional children, several actions should be taken to

—Establish placement priorities
—Identify and specify the responsibilities of government agencies

—Delineate the responsibilities of private agencies
—Establish rates and fees for services
—Assure equity of access
—Provide staff training to assure the successful integration of exceptional children in proportion to their presence in the eligible population

Federal actions needed:

—Insist on equal access in use of federal funds, especially Title XX Social Services Block Grants: e.g., any funds spent on child care must serve exceptional children in proportion to their presense in the eligible population
—Use HHS discretionary grants to fund model mainstreaming and special child care programs; collect data and build a dissemination effort
—Use Department of Education Handicapped Children's Early Education Program funds to target child care programs
—Tie HHS child care training funds to equal access requirements for both subsidized care and state licensing
—Extend the 504 regulations to cover children in child care settings
—Strengthen and increase child care support services available to job trainees in the Job Training Partnership Program; insist that exceptional children be served by child care services

In addition to these federal actions, state and local government must also make changes to assure access of these children and their families to child care services. The following testimony makes recommendations to government in general.

The Congress, the Select Committee, and the federal administration can provide leadership in part by calling for state and local governments to make appropriate changes in their licensing and social service programs.

Persons interested in these issues are encouraged to contact the California Child Development Programs Advisory Committee, 915 Capitol Mall, Room 250, Sacramento, California 95814; 916-322-8181.

I. INTRODUCTION

Currently no government policy directs, shapes, or assists a parent's search for child care for an exceptional child. None guides the staff development of child care programs that enroll exceptional children. Reimbursement rates for care are fragmentarily addressed in some state's codes.

Federal and state governments should develop policies to address the child care needs of exceptional children and their families. This policy should include the identification and development of resources to provide care; the policy should define a placement process; and, the policy should establish a reimbursement system.

A coherent policy in this human service area would increase the availability of care, would delineate and promote working relationships among government agencies as well as among community agencies, and would assure that parents of exceptional and of non-handicapped children have equal access to child care.

If one approaches this area by looking at one state's numbers and by listening to parents' testimony, one appreciates the need for a policy here and for an increase in child care provided to exceptional children. The numbers, while incomplete, provide an initial needs assessment.

> 325,000 California pupils, kindergarten through twelfth grade, receive special education services. They comprise nearly 8% of the State's K-12 enrollment.
>
> 18,850 children under five years of age receive special education services through Department of Education programs.
>
> 18,736 Developmental Services clients are of school age.
>
> 6,988 Developmental Services clients are under age five. It is likely that all school-aged clients and many clients under five receive some form of special education services.
>
> Parallel data from the State Office of Child Development show that 2,769 individuals in subsidized child care were reported as handicapped, in March 1979. These children comprise 4% of the children in subsidized child care.

While conclusions must be qualified, it appears clear that exceptional children are proportionately underserved by California's subsidized child care programs. While 8% of the K-12 student population receives special education services, only 4% of the child care recipients are identified as handicapped. These comparative discrepancies worsen when one looks at services to severely handicapped children: while 1.4% of the K-12 population are identified as severely handicapped, only 0.4% of the recipients of subsidized child care are so identified.

The California Department of Education recognized the same discrepancies in its 1980 Annual Report on Publicly Subsidized Child Care Services. The Department wrote to the Legislature:

> the proportion of handicapped children enrolled in publicly funded child care centers and homes (4 percent) was less than half of those enrolled in the regular school population (10 percent). This finding reveals a serious deficit in the child care services available to these children . . . extensive research has shown that the sooner handicapped children are enrolled in remediation programs, the sooner their chances to realize their potential is increased. The expansion of Child Development Programs could, therefore, be a real benefit to these children and their families. (p. 57)

One can estimate parents' needs by looking at employment figures and by recognizing the importance of respite, particularly for parents of severely handicapped children. Currently, more than half of California's women are in the workforce. If the mothers of young handicapped children are to have equal access to employment, then child care spaces must increase. Again, extrapolations give an estimation of need: if 1.5 percent of the population is severely handicapped and an additional 4 to 7 percent are handicapped, then parents of exceptional infants and preschoolers will need up to 55,000 spaces for child care. Of these children, about 10,000 would be severely handicapped.[1]

If parents of exceptional school-aged children, 5 through 14 years of age, participate in the labor force in the same proportion as parents of non-handicapped children, then up to 130,000 schoool-age exceptional children would need care and supervision for part of the day. Nearly 25,000 of them would be severely handicapped. Further if we assume that severely handicapped teenagers require care up to age 18 or 21, then an additional 18,000 severely handicapped older adolescents would have working parents and could well need continuing child care.

The numbers are, of course, gross estimates. Not all school children receiving special education services were diagnosed as exceptional when they were younger then five years of age. Some handicapping conditions only impair children's academic progress and are not evident before children attend school. The identification of special needs may come when a child is in school.

Also, for protective reasons, some mothers of exceptional children choose to remain out of the labor force, thus reducing the number of child care spaces necessary. This however, is presently not a matter of choice; rather, staying at home with their child is a necessity forced upon them because no child care is available. Public policy should offer this choice.

The numbers cited above suggest sketchily the amount of child care needed for exceptional children in order to give equal access to care to all parents who choose to work. In addition, parents of handicapped children, especially severely handicapped children, need respite, even if they are not in the workforce. Again, about 1.5% of the population of children and youth have severe handicaps. (Here we include children who are severely mentally retarded, severely emotionally disturbed, deaf, blind, orthopedically impaired, multiple handicapped, and chronically ill.) Approximately 100,000 children, birth through twenty-one years of age, are severely handicapped. Their parents needs for respite care include simple sitter services for afternoons or evenings, care for occasional weekends, and provision for week long or two-week long respite to prevent burnout. These respite options serve to support parents who choose to care for their children at home instead of utilizing twenty-four hour placement services for continuous care.

To assess the need for care one must also turn from statistics to parental opinion. While at work on this testimony, we listened to parents who described their needs for care and the positive difference in their lives that child care brings. A parent from San Jose spoke with eloquence at a hearing:

> To what extent is a defacto isolation of parents and their handicapped children occurring?
>
> Are women being denied the opportunity to use and celebrate their talents, to enter the labor force, to contribute to their families' financial resources, or otherwise to find a daily respite from what may be a lifelong responsibility? Are children with more than minimal handicaps being

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[1] These extrapolations call for explanation. California's population of 0-4 year olds is about 1,730,000. If 8% of these children have handicaps and 40% have working mothers, then 55,000 will need child care. And so forth with other populations.

denied the opportunity to experience life outside home and the usual clinical settings?

From this parent and others who spoke to the Committee, one get a sense of urgency. It is time for a governmental policy which gives direction to agencies and promotes the development of resources.

II. VALUES

We have identified three major values to guide public policy in this arena:

1. Family unity is a primary value to society, and government policies must support the retention of the family as a unit. Enabling a family to maintain a disabled family member at home is part of the government's rsponsibility. In the field of social services, for example, the family reunification provisions of PL 96-272 promote similar values.

2. The desirable deinstitutionalization of our disabled citizens requires the provision of community services to realize its public policy implications.

3. We must provide equal access to both exceptional and non-handicapped children. Whenever we provide subsidized child care to the children of low-income working families, it must be open to children with disabilities as well as to children without handicaps.

The Committee has several goals in addition to our broad goal of establishing public policy for child care for exceptional children. These goals include:

more nearly meeting parents' child care needs expanding the number and kinds of resources available to parents

assuring a systematic response once a family's need is identified

assuring that the quality of care provided is sufficient to maintain or enhance each child's development

assuring that the care is affordable to the family through the establishment of a free structure designed specifically for the populations to be served.

III. RECOMMENDATIONS

To arrive at its recommendations, the Committee used the following definition of child care:

Child care for exceptional children equates with child care for any child: supervision which substitutes for that given by the child's primary care provider and which meets the child's needs for a safe, secure, and stimulating environment which is developmentally appropriate.

Child care settings include the child's own home, a foster home, a family care home, a child care center, a day nursery, or the respite facility of another care provider.

The need for care is time-limited and is usually in increments of fewer than 24 hours per day. Exceptions to this time limit are important: child care may be needed in full day increments for a limited period when the primary care provider is away from home in training, seeking work or hospitalized, or because of the respite need of the primary care provider or of the child.

The need is for substitute care rather than for other types of special education services or therapies which are normally provided in other settings.

The definition indicates that the Committee's attention is on the need for respite care as well as for care while parents work. It also indicates that the Committee is not, in this testimony, addressing the need to extend special education services to young children with exceptional needs.

LICENSING

In its review of child care, the Committee found that the current state child care licensing regulations may well restrict the amount of child care available to exceptional children. Child care centers and family day care homes which want to enroll an exceptional child must seek permission to do so from a licensing worker, and the program must demonstrate that the child can be included without danger to self or others.

The Committee recommends that federal regulations or guidelines be revised to allow programs to enroll exceptional children at the licensed program's discretion. This national directive is needed both for centers and for family day care homes.

With all programs allowed to include exceptional children, the Committee also recommends that all child care programs open themselves to including exceptional children: there should be no discrimination against a child who has a disability. Some communities currently have programs which provide care exclusively to a high percentage of exceptional children. More such care is needed, particularly for older exceptional children. We should assure places for those children who cannot be integrated with their peers.

Children's Ages, Severity of Handicap, and Native Language

The following general principles were supported by public testimony to us:

Many exceptional children will fit into integrated child care settings without assistance.

Others can be mainstreamed with help.

A minority will be served best in child care programs designed exclusively for individuals with special needs.

The Committee recognizes four groups of children whose needs define the four major care arrangements required if we are to provide care to exceptional children in an appropriate and coordinated setting.

1. Six to twelve year old children.—These children are in school programs and need child care before and after school. These child care programs need not be staffed by specialists. Special education services should be provided during the school day. Most exceptional children in this age group can be served well in regular programs. Child care in integrated settings can offer things to these children that their special classes cannot: every day activities, work and self-help skills, and social interactions are of great value to the children themselves.
2. Twelve to twenty-one year olds.—These children and youth, whose parents work, need care, but cannot be integrated into most regular child care settings because of their ages. They will need programs designed for exceptional persons, but again, because they receive special services during the school day, their day care programs should be typical. Socialization and recreation needs may well be paramount for children in these programs.
3. Three to five year old children with intensive needs.—These children qualify for public school special education services. Again, as with the first two groups, their principal need is for safe and supportive child care before and after their special education programs. Again, as with the first two groups, their principal need is for safe and supportive child care before and after their special education programs. (Before some public schools and private agencies offer special services to children younger than three, there will be a few infants and toddlers in this group as well.)
4. Infants to five year olds unserved by special programs.—These exceptional children need full day care. Because there may be no special services available to them from public schools—aside from assessment and referral—child care providers may need to plan and carry out unique programs for these children.

For each group, staff training will be important. And within each group, some children will need care in programs separate from their non-handicapped peers.

In each of these situations, a child and parents whose language is other than English will need to work with staff who speak the child and family's language and who are sensitive to cultural differences. The linguistic and cultural knowledge of staff is required to plan a child's program well—with an understanding of disabilities within a child's culture—to include parents and other family members appropriately, and to assist parents to understand the local special education system into which the child may go.

Respite

Almost all parents of exceptional children, particularly of severely handicapped children, share the need for respite care—including parents outside the workforce as well as parents employed outside their homes.

The needed respite takes several forms: time to shop, time for evenings of entertainment, time for an occasional weekend away, and time for rare vacations. Those who need respite are, primarily, the parents of exceptional children; but included in this group are other primary care givers—grandparents or aunts, foster parents and group-home operators. These needs suggest a range of child care resources:

Regular child care program hours

Drop-in care

Care provided in a child's own home, and

Residential arrangements, including temporary foster homes, which are in keeping with the concept of the least restrictive environment which meets a child's needs.

To develop this range of resources, government as well as churches and other community-service organizations must undertake several actions:

The Developmental Disabilities system should address the need for respite care for their clients by providing it on a priority equal to all other services.

Such a policy makes good fiscal sense at the same time that it realizes a humanitarian goal.

In addition, the State Councils for Developmental Disabilities should commit themselves publicly on the need for respite care.

Planners within Health and Human Services and the State departments of Mental Health as well as others working with the Department should recognize the need for respite care and should examine thoroughly the best ways for funds to provide respite care for mental health clients and their families.

Similarly, participants in Health and Human Services and the State departments of Health Services programs should incorporate respite care into Medi-Cal services and other maternal and child health programs. Among the children who need respite care are the chronically and terminally ill.

Children in school programs whose parents are not working but who need occasional respite beyond the length of the school day should be able to use existing child care centers on a fee for service basis. Government offices administering subsidized child care can, where space permits, include children for a few hours on an irregular basis. Parent fees charged should not be more than the marketplace's cost of care. In addition, private unsubsidized programs should open their doors on a fee for service basis to children whose parents need respite. Child care resource and referral agencies can provide parents with lists of willing programs.

Churches and other community service agencies should consider adding well-publicized evening care programs for exceptional children and their siblings. Such programs can take place at a central location, include the provision of in-house care, or a combination of these. These programs could also charge fees. Parents who testified to the Committee indicated a willingness to pay for such care which does not now exist in their communities.

Assuring the provision of daily child care

In making its recommendations on the best ways to meet the ongoing child care needs of working parents of exceptional children, the Committee holds that the principle responsibility for assisting parents to locate and/or to pay part or all of the cost of care rests with the service systems most directly concerned with the child's presenting handicap. Children who are clients of the developmental disability system should receive child care assistance through their case managers as part of their Individual Program Plans (IPP). Children in the mental health system should be able to turn to their county mental health agencies. Children receiving public school special education services should have child care considered as part of their individual Education Plans (IEP). Likewise, children served by health services programs should have their child care needs identified and located or purchased through these programs.

To realize these responsibilities, the Committee makes several recommendations:

1. The developmental disability system must assist families to secure child care.

   They must recognize child care as a "basic and essential service."

   Each developmental disability client, birth through twenty-one years of age, who needs child care must have that need identified in his or her IPP.

   Client case managers must assist parents in locating the most appropriate child care arrangements.

   All developmental disability case managers should be aware of the services available from child care resource and referral programs.

   Where necessary the developmental disabilities system must pay for these child care services.

In making these recommendations, the Committee recognizes that child care is equally a service to children and to their parents. Child care promotes a child's development. In some cases it permits a family to remain intact rather than seek 24-hour placement for their child. In sum, child care must be an integral part of the IPP of any child whose parents are employed, in training, or in need of respite from the excessive demands of raising a substantially handicapped offspring.

2. The mental health system must assist families to secure child care.

   In planning a child's program; the mental health worker and the child's parents must consider child care needs as an integral part of the child and family's service needs.

   Where necessary, funding must be available to pay some or all of the costs of child care for these clients.

   The mental health system should provide mental health consultation and support to staff members of centers serving exceptional children.

3. Subsidized child care (Title XX) must increase its support of child care for exceptional children. Special efforts to expand subsidized child services for exceptional children must occur until the percentage of subsidized children who are handicapped equals the percentage of the K–12 enrollment who receive special education services. To accomplish this goal, as well as to increase and improve child care services to exceptional children, the Committee recommends several legislative, administrative, and programmatic actions.

Exceptional children must become a priority for child care services.

The state agency administering Title XX funds must provide technical assistance to its contracting agencies to assist them to enroll additional exceptional children and to serve well those who are enrolled.

This technical assistance should be provided via contracts with capable T. A. agencies. Government has several resources for such a contract or set of contracts: a special training program developed to meet the service needs of family day care providers, Head Start's Resource Access Project, and child care agencies which provide technical assistance to other subidized child care programs.

Preschool Incentive Grant funds from PL 94–142 could be used for these purposes if necessary.

4. The federal and state offices of Special Education can help meet the child care needs of exceptional children.

With technical assistance from federal and state government, local districts can identify child care as a child's need or Individual Education Plans (IEPs), can assist parents to find child care by working closely with the local child care information and referral agency, can assist local child care agencies to enroll exceptional children, and can work with school district child development programs to include additional exceptional children.

The Committee recommends that programs such as Berkeley, CA Unified Schools' joint children's center/special education program, be a national model. In this program, special education teachers, aides, and pupils are integrated fully with the teachers, aides, and children of the district's largest child care center. Similar integration can take place within Head Start, Title I Pre-Kindergarten, and other child development programs.[1]

Funding, Fees, and Rates

A middle ground between no fees and full cost seems most appropriate for parents whose exceptional children require child care. Parents who testified at the Committee's hearings recommended a fee schedule which includes:

A means test;

No charges to families below the poverty level;

A sliding scale for families between the poverty level and the State median income level; and

A maximum fee no greater than the "marketplace cost" of child care for a non-handicapped child.

This last figure would make this fee scale unique. For example, in most California communities, child care currently costs about $50/week for preschool aged child who is not handicapped. If an exceptional child's program cost $75/week, the parents would still pay no more than $50 and the difference would be met through public resources.

The Committee recommends the adoption of such a scale.

IV. Conclusion

The Committee focused mainly on children who are substantially handicapped. This report gives attention to the needs of these children and their parents. Among the recommendations which address these needs most directly, are:

1. recognition of the necessity for communities to establish and to support after-school programs for older exceptional children and youth;
2. attention to family's respite needs; and,
3. school districts pursuit of a model which integrates children's centers and special day programs which are part of the special education program.

However, children with substantial handicaps were not the Committee's sole concern, and the need to serve those children in child care programs was not the only need identified. About five out of every six exceptional children are either mildly or moderately delayed or disabled. These children should have immediate access to all child care and development programs, subsidized and nonsubsidized.

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[1] The Berkeley program is a model of integration during regular school hours. However, funds are insufficient to provide extended day care to the program's disabled children.

If our nation is to meet the Committee's goals and recommendations, leadership from the professional associations, the college campuses, the State Departments of Education, the State Councils on Developmental Disabilities, Legislatures, Governors, Congress and the President will be needed.

PREPARED STATEMENT OF LEONARD D. BORMAN, PH.D., PRESIDENT AND FOUNDER OF THE SELF-HELP CENTER, EVANSTON, IL

My name is Leonard D. Borman, Ph.D., and I am President and Founder of the Self-Help Center located in Evanston, Illinois. It was established in 1974 at Northwestern University as the first such clearinghouse in the nation, and we spun off in 1980 to become an independent non-for-profit agency. We have become a model for the establishment of similar clearinghouses in two dozen places around the United States, three of which are statewide in scope. A bill has been introduced in the current session of the Illinois Assembly to establish a statewide clearinghouse in Illinois.

These self-help centers or clearinghouses have become "new social instruments" to help in the formation of self-help support groups for persons and their families facing a variety of conditions and afflictions. In a recent handbook which we are publishing focusing on resources for the developmentally disabled and handicapped in the state of Illinois, we identified over 400 groups for nearly 134 distinct developmental disability conditions in the state of Illinois. The experience of the Self-Help Center, as well as that of other centers, has demonstrated three major strategies for strengthening, linking, and sustaining self-help/mutual aid groups. The first is an information and referral strategy that provides professionals, the public, and the media with information on gaining access to self-help groups. This is accomplished primarily through the publication of an updated directory and provision of a 24-hour telephone service.

The second strategy used by self-help centers is to provide consultation and training in the formation of new groups. This is training directed toward both professionals and laymen, and is designed to convey an understanding of the unique nature of the self-help process and its application to specific populations.

The third strategy is to provide assistance to groups already formed. Self-help centers can help existing groups to expand their networks, increase recruitment, strengthen organizational capacity, or produce new educational materials.

In recent years, an impressive array of research findings has indicated that these self-help support groups provide enormous benefits to the participants and the members of their families. Not only do these groups provide important up-to-date information, but they provide a network of emotional and social support to persons coping with a variety of conditions. They serve to link members to an active exchange network that enhances functioning and mitigates distress. Not only do they operate through meetings that are held at regular times, but they provide access to their members and others through telephones, newsletters, friendly visits, special gatherings, or conventions. Unlike most forms of help and support offered through neighborhoods, agencies, or families, self-help/mutual aid groups represent dispersed networks that have the potential of developing affiliations nationwide.

Since the development of Al-Anon in 1954, it has become clear that self-help/mutual aid groups have the potential to aid family members who are "one step removed" from an individual who suffers from a particular condition or affliction. Over the past 30 years, a great range of groups has been formed to help parents, children, and other family members to cope with the special problems presented by a family member. Research of such groups indicates that participants are better informed and more involved in relevant communication networks than non participants.

Research on self-help groups also reveals that these groups supplement and do not supplant professional services. At the same time, professionals and agencies can be helpful in encouraging the formation of groups, making information available to their constituents, and helping to publicize the value and presence of such groups in their communities.

Basic financial support for self-help clearinghouses and self-help groups has come primarily from the members themselves, local, and private sources. At the same time, it appears clear that there is a role for public support at various levels including the federal government. As in Canada, federal support could provide help in the publication of information on groups, the development of directories, the utilization of computerized resources, and providing access to 800 telephones lines on the location of groups. In addition, opportunities for workshops and conferences could be supported through federal agency funds so as to enhance the dissemination or utilization of self-help groups throughout the land. Research and the publication of findings could also be supported.

In summary, the findings on self-help groups are impressive. They represent low-cost or no-cost resources for vast segments of our population coping with developmental disabilities, chronic conditions, and other afflications. They strengthen the voluntary component of our society while providing new resources to be utilized by professionals and agencies.

I would hope that the Senate Select Committee would give special attention to this new and vital resource that could be strengthened across the country.

NATIONAL CHILD ABUSE COALITION,
Washington, DC, March 31, 1985.

ANN ROSEWATER,
Select Committee on Children, Youth and Families, 385 House Annex 2, U.S. House of Representatives, Washington, DC.

DEAR ANN: In talking to Judy Weiss this week she mentioned that you were interested in information about abuse of disabled children. While I do not have any material on the incidence of abuse among families with a disabled child, other than an accepted recognition that those children are highly at risk of abuse, I do want to pass along some information on programs to prevent abuse of handicapped children.

First is a copy of relevant pages from a new publication of the National Committee called Child Care and the Family. Second is a collection of articles about a terrific program in San Antonio called Project Any Baby Can that has had great success in helping parents with disabled children.

I wish I could go to Anaheim for the hearing. I'm leaving for vacation in California on Tuesday and coming home just before then.

It was wonderful to see you at the Hexagon show. Thank you very much for coming. We had quite a success this year and you helped!

Best regards,

THOMAS L. BIRCH, *Legislative Counsel.*

Child Care and the Family

David B. Friedman, June S. Sale, and Vivian Weinstein

National Committee for
Prevention of Child Abuse

the United States there are undoubtedly many 12- and 13-year-olds who are capable of baby-sitting. In general, however, school-aged children do not have the knowledge or mature adjustment to be given the full responsibility for child care. Also, shouldering this burden in some cases robs children of important childhood experiences.

The danger of using untrained and inappropriate baby-sitters because of the potential for accidents and child abuse has been recognized only recently. Many pediatricians and other health professionals working with families place this issue high on their list of subjects to be discussed with parents. In some communities the Red Cross, the schools, and youth-serving agencies such as the Girl Scouts, the Boy Scouts, and the Camp Fire Girls have organized classes to improve the quality of baby-sitting among teenagers.

Parents should exercise care in choosing baby-sitters. Once selected, the sitter should be given instructions regarding activities with the child and disciplining the child. The sitter's behavior should also be clearly circumscribed. Drinking, smoking, using drugs, using the telephone to talk to friends, entertaining, and other potentially dangerous activities should be forbidden. It is also important for the sitter to have *in writing* the telephone number where the parents or some other responsible adult can be reached as well as emergency numbers for the police, paramedics, and fire department.

It would be wonderful if all parents knew where to obtain baby-sitting services. This would minimize the possibility that children would be left alone or left in the care of inappropriate or incompetent adults or children. Every community and neighborhood should have a pool of reliable, experienced baby-sitters. Alternatively, friends or neighbors could band together to exchange baby-sitting services. Helping to develop such an arrangement or pool or hot line could be an exciting and worthwhile project for a group of community volunteers.

Handicapped Children[3]

There are many working families that require before and after school care, night care, weekend care, and respite care. Similarly, there are families that require care for children who have needs different from the needs of their contemporaries. Day care should be structured to meet the needs of all families, including those with children who have special needs. These children are at higher risk for abuse, and child care can be important to the prevention of such abuse. An example of a program that meets the needs of such parents is Project ABC (Any Baby Can), which links children with special needs to appropriate services at the earliest age possible.*

Services for children with developmental and physical handicaps are rapidly changing as educational, health, therapeutic, and social agencies adopt programs to meet the mandates of Public Law 94-142 (Education for All Handicapped Children Act) and other federal and state laws. These laws promote the inclusion of all children in programs that meet their developmental needs regardless of their handicaps or medical records.

Parents can be helped greatly to accept their child's disability in a supportive setting where concerns and common problems can be shared among parents during visits, conferences, and parent get-togethers. No one can argue against the positive effects of providing a warm, loving, communicating environment for children experiencing mental, sensory, motor, or emotional handicaps or children with health impairments. Day care can provide for the majority of needs for the handicapped child under 24 months of age, although some children, such as the deaf child, may require special activities to meet specific needs, and appropriate consultation should be sought.

As the handicapped child grows older, specific interventions beyond the capability of conventional child care programs may be required. The child care staff, working with appropriate consultants, can devise mechanisms to ensure that all children are appropriately assessed to detect delays in communication and in social, motor, and affective skills. If atypical patterns are detected or suspected, consultation should be sought with health and educational professionals skilled not only in diagnosis but also in assessing functional abilities and developing appropriate intervention plans and services.

As the child increases in age, the specialized needs of the child often become more pronounced. Day care programs must establish a policy in consultation with parents and health and educational personnel regarding the program's ability to meet individual needs. For school-age children the educational and therapeutic needs of the child most frequently are met by the public schools, and the child care center provides the before and after school supervision required by working parents. Most schools are implementing mainstreaming programs, and mainstreamed handicapped children may function very well in day care programs along with nonhandicapped children.

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*Further information about Project ABC can be obtained from the San Antonio Chapter of NCPCA, 1011 W. Woodlawn, San Antonio, TX 78201. (512) 732-1051

The majority of children with mild handicaps are not identified by age 24 or 36 months. These include children with mild mental retardation, mild-to-moderate speech and language disorders, and learning disabilities. These children are best served in settings that enhance their total development; day care programs of high quality provide such settings. Severely handicapped children, on the other hand, may require more specialized day care that can be provided only by a trained family day care provider or in a special day care center.

An often neglected aspect of day care is respite care – the service provided a family on a short-term basis to allow a parent a few hours of relief from the care of a severely handicapped child. A very young child generally poses few problems during such respite care periods, but the older, ambulatory child may need more specialized care and supervision. Each program must carefully evaluate its ability to provide high quality care for these children with special needs.

It is universally recognized that handicapped children of all ages are at greater risk for abuse. Caring for a child with special needs creates great stress in families, and child care, both respite and ongoing, has been shown to be one of the best approaches to preventing such child abuse and neglect.

Crisis Child Care

Another form of child care is the crisis nursery or the crisis child care center. These are centers to which parents who feel overwhelming emotional stress or pressure can bring their children until they are able to cope. This gives parents the opportunity to express their anger and frustration appropriately and to pull themselves together rather than exploding and taking their feelings out on their children.

The first crisis center was established in Denver, Colorado, in 1973 as part of an overall child abuse prevention package. The center has remained an integral part of this pioneer program. Since 1973 many crisis centers have sprung up across the country, such as the El Paso Crisis Nursery in Texas. Some centers provide minimal services, their main purpose being to provide time away from their children for harried parents. Others provide broader services for both parent and child. All can be truly effective only if they are open around the clock and if they establish appropriate ties with other community services. For these reasons, an established child care facility, especially one associated with

[From the San Antonio Express News, Tuesday, May 29, 1984]

PROJECT ABC ASSISTS FAMILIES

(By Edna McGaffey)

Nicole and Nick Anthony Almendarez will be four years old in July but unlike other youngsters their age, they are not talking and running about.

The twins, born three months premature to Jackie and Nick Almendarez, spent the early months of their life in a respirator. When they were about a year old, they developed cerebral palsy and other severe complications. In the meantime, the Almendarezes decided to have another child which is 10 months old.

Before the twins could be released from the hospital, Jackie had to learn to drain the fluid from Nicole's head (she has water on the brain and is mentally retarded) and to feed Nick Anthony through a tube in his stomach and to clean and change the breathing tube in his trachea.

Monumental problems like the ones the Almendarezes have are being faced by many families, Dr. Marian Sokol, director of Project Any Baby Can (ABC), says.

"Programs exist in the community to help these handicapped children, but parents often don't know how to find the needed service. For this reason the San Antonio Coalition for Children, Youth and Families established Project ABC to identify and secure help for the many handicapped and high risk babies in the community."

Sokol says medical advances have made it possible to save the lives of more premature babies. Unfortunately, these infants often develop long-term disabilities from early lack of oxygen to the brain.

Respiratory disease is prevalent in premature infants, and they are susceptible to cerebral palsy. Auditory impairment and delayed language development also are common.

"Project ABC serves as a central clearing house that refers families to 150 agencies, clinics and support groups," Sokol says. "We 'case manage' clients until they receive needed help."

Project ABC is assisting the Almendarez family obtain respite care on a sliding fee basis. As a temporary measure, the project paid for a nurse so the parents could go out together for an evening—something they had not been able to do for a long time.

"Initially, we concentrated on serving preschool children, but we are beginning to focus on early childhood," Sokol says.

Pre-teens sometimes develop disorders that are difficult to diagnose and require long-term specialized care. For example, Tony Sollars, 9, son of Steve and Candy Sollars, began grimacing, arm jerking and making strange throat noises about three years ago.

Initially, teachers and physicians thought Tony was a behavioral problem. Finally, after much effort, the Sollars found a doctor who recognized that Tony had Tourette Syndrome, a rare neurological disorder which can be disabling.

Candy says this disability manifests itself by multiple transitory tics, such as those mentioned above, that change from one area of the body to another after several days or weeks. In advanced stages the disorder may cause the loss of the ability to control language, resulting in repeating and the use of obscenities. The condition can be controlled fairly well with medication.

Tourette Syndrome shows up in children around age 6 or 7, Candy explained. Recently, her other child, a daughter, age 7, was diagnosed as having the disorder.

After reading, studying and coping with Tourette Syndrome for three years, Steve and Candy organized a local support group in April. It is the Central Texas Area Chapter of the National Tourette Syndrome Association. Already 150 people are on the mailing list.

Candy says, "We are working through Project ABC to let families know about our group. We can put families in touch with local physicians familiar with the disorder, and help parents learn to live with children who have it."

Project ABC was established as a model effort two years ago because educators, therapists and social workers were convinced a need existed for the service.

"At that time we were not aware of the intensity of the problems faced by families of multiple handicapped children," Sokol says. "More than 800 babies have been provided help, and we receive 50 new cases each month.

"Parents don't expect their children to be less than physically and mentally perfect. When their child is medically impaired, it's a shock. They need to become experts in an unfamiliar area.

"Hopefully, we can make the parents' job easier by taking the frustration out of applying for financial aid and securing help from social service agencies."

Project ABC offices are located in the Santa Rosa Children's Hospital. The San Antonio Coalition for Children, Youth and Families is the non-profit umbrella agency through which the federal grant was received for the model project.

[From the San Antonio Light, Sept. 21, 1984]

Project ABC Recognized for Service

(By Keri Guten)

It was supposed to be a surprise. The engraver blew it, however, by calling the Project ABC office to see how they wanted to be listed on the plaque they would be getting from the United States Department of Health and Human Services.

"What award?" they asked in unison from their office in the Children's Hospital Ambulatory Care Center at Santa Rosa Hospital.

Presented by John Daeley before Mayor Henry Cisneros at City Hall yesterday, the award is the DHHS' Regional Director's Award from the Administration on Developmental Disabilities. It is the top award for excellence within the five-state region.

"Project ABC was chosen because of activities that provide assistance to children needing referral service, but they were chosen mostly because they involve volunteers and the private sector. There is a push from the federal government to get volunteers involved because of planned cutbacks in funding," says Lauro Guerra, program specialist with the Administration on Developmental Disabilities.

Project ABC began three years ago as a model project under the auspices of the San Antonio Coalition for Children, Youth and Families. Its purpose is to act as a clearinghouse for parents with children age 0 to 3 experiencing development problems.

Because of the diversity of agencies and also because of overlapping of some services, parents were often unsure of where to turn to proper assistance with problems. By gathering all agencies under the umbrella of Project ABC, parents now have one central office which deals with referrals and guides parents to the proper agency for the best service possible.

The service is free. Support comes from the Texas Developmental Disabilities Program, the City of San Antonio, the Hogg Foundation in Austin, private donors and, as of this year, from the United Way. However, funding from the TDDH and the Hogg Foundation ends this year and other sources will need to be found to augment about $60,000 of the 1984 budget of $167,000.

"It will be beneficial for those who give contributions to see the kind of recognition we've received," says Esther Lares, fiscal manager, of the regional award.

Awards aside, the figures supplied by the staff's sixth full-time member—the computer—speaks well for the success of the project.

Since the program began in June of 1982, 977 cases have been handled, resulting in 1,400 referrals to more than 197 agencies. The success rate runs around 63 percent of those referred receiving direct help.

[From This Week, Sept. 12, 1984]

Know a Baby Who Needs Help? Call Project ABC—Dial 228-2ABC

(By Marjorie George)

Imagine the anguish of having your baby born with—or develop—a debilitating handicap.

Now imagine the technology to help your baby exists, the medical breakthroughs have been made and programs have been implemented, but your baby isn't benefitting because you don't know how to get into the system.

Imagine the frustration of not being in contact with special schools, state programs or more than 140 agencies in San Antonio who might be able to help your child, only because you don't know who to call or what questions to ask.

This was the nightmare that used to exist for many parents in San Antonio. It is the reason Project ABC was founded.

Project ABC—Any Baby Can—is a clearinghouse, a networking organization that puts families in touch with those who can help. It concentrates on physically handicapped, developmentally delayed, mentally retarded and high risk infants and children of preschool age.

To fully understand Project ABC you must know how it came into being. In 1981, Marian Sokol, Ph.D., was teaching in the early childhood and special education programs at San Antonio College. She was also involved with the San Antonio Coalition for Children, Youth and Families. That year, a task force of the Coalition wanted to do something for parents of special children. "We decided the best way to find out what we should do, what these parents really needed, was to ask them," says Sokol. "We were not prepared for what we heard."

What they heard was that at a time when parents were faced with the most critical decisions regarding their special children, they didn't know where to go or what questions to ask. "Because our society has become so sophisticated, instead of dealing with one doctor, they were dealing with several specialists, and nobody was looking at the total situation," says Sokol. "We talked to one mother who made 22 phone calls to find out where to go for help for her child."

Agencies who couldn't help a child might not know other agencies who could help. Or a child would get into a special program, only to find transportation was not provided and parents had no way of getting the child to the program.

While all school districts must serve handicapped children ages 3 to 21, each district has its variances. In some districts you go to the central office, in others you go to the nearest elementary school, in others you go to a pupil appraisal center. And, if the child is blind or deaf, it can be served starting from birth.

"This sort of thing caused a lot of frustration, confusion and anger on the part of parents," says Sokol.

Being primarily educators, the task force decided to publish an information booklet. For the next eight months, the 12 volunteers looked for every program for special children that existed in San Antonio. The task was monumental, and frustrating. When it was decided to include which day care centers will take handicapped children, for instance, they went to the Texas Department of Human Resources who licenses day care centers. That agency said it would love to tell the group what day centers took handicapped children, but it didn't know, instead of information, TDHR gave the group 400 stamps.

Eventually the task was completed, and the book printed. But instead of the job being completed, it was just beginning. "The San Antonio Light ran a story on the book," recalls Sokol, "and we were just deluged. In two days I got 37 phone calls from parents who needed this type of information and more.

The temporary project became a permanent one, to be called Project ABC—Any Baby Can—because Marian Sokol believes any baby can reach his maximum potential with the right help. Sokol left her teaching job to become project director.

Since Project ABC opened its doors in early 1982, the organization has referred over 1,000 babies in a thousand different ways.

There are the twins, Jason and Jacob Herrera who were born premature and developed respiratory problems. When Jason went through a six-week battle with a bacterial infection, Project ABC was in touch with the young mother almost daily.

There is Juan Jose Pena who was identified at birth as having periods of apnea, cessation of breathing known commonly as sudden infant death syndrome. Being on an infant monitor would identify those periods so that his mother could revive him—literally save his life. The monitors are readily available, but his mother didn't have the $200 to $300 a month to rent the machine. ABC loaned the monitor (they own four of them) and Abbey Medical graciously maintains them at no charge to parents or ABC.

There is the child whose family called last week because he has a speech problem. He'll be four in November. His parents didn't know how to contact the school district or what services the district could provide. They didn't know that at age three the child was eligible for speech therapy. ABC set up an appointment for the child with the district; he'll be seen next week.

There is the family with seven children, the youngest of whom has been born with Downs Syndrome. ABC will try to get the child into an early intervention program, will place a dozen or more phone calls, will find out where the waiting lists are shortest, will look at transportation needs.

There is the father of a young child who was developing right on schedule until, suddenly, at 18 months of age the child began having seizures and convulsions, eventually regressing to a developmental level of five months. Not only did Project ABC find the agencies that would help the child, they dealt, very lovingly, with the denial the parents were experiencing.

The father said it all when he wrote, "If prospective parents were given one wish, most would wish for a child who is healthy and whole. When a child is born with a disability or suffers an impairment at an early age, the impact on the entire family is devastating. Parents are simply not prepared for it. There are few answers, major new responsibilities, and a general feeling of helplessness; parents don't know where to turn, or what to do next . . ."

The Project ABC staff consists of six, including a degreed social worker with 22 years experience and an assistant who has personally experienced being a handicapped child.

The staff "case manages" each of the 45 to 50 referrals each month. That means after being in daily contact with parents until the child's needs are met or he is placed in an appropriate program. If they set up an appointment for Johnny to see an orthopedic doctor on Tuesday, on Wednesday ABC will call to see if the appointment was kept and what the results were. If Johnny then needs special shoes and the family can't afford them. Project ABC will go about trying to find some at little or no cost. When Johnny's problems have all been adequately solved, the case is "closed." Of the 1,000 referrals so far, about 600 are closed cases.

In addition to these cases, another 45 to 50 calls for information only come in each month. Perhaps it is a mother looking for a summer camp for a handicapped child, or a parent wanting to find a day care center on the northwest side of town. These calls are documented, but not case managed.

Because the agency is there to funnel through, a lot of other things also have happened. Last December they were asked if they could use some shoes for handicapped children. When they said of course they could, 400 pair of shoes were delivered. On another occasion, three pedodontists wanted to donate their time during dental health month. "So we had a whole morning of dental screening of handicapped children at no charge," says Sokol.

Parent support groups also have been spawned through ABC. The parents of a child with Tourette Syndrome—a disability that manifests itself by multiple tics, grimacing, arm jerking and throat noises—started a support group of parents of children who have to live with this rare disease. In April, the Central Texas Area Chapter of the National Tourette Syndrome Association was formed; it already has 150 people on its mailing list. Another mother is currently starting a support group for mothers of infants on apnea monitors.

Other needs also have been identified. One of the real needs of parents of disbabled children, says Sokol, and one that is often overlooked, is respite care, just getting out of the house occasionally. So Project ABC has trained a group of Lee High School juniors and seniors as babysitters. The students had already taken child care and development courses, but they spent additional long hours learning how to care for the handicapped child. Their services are not free, but they are available.

A crisis fund was developed when parents who lost a baby requested donations be sent to ABC in lieu of flowers. It has been added to and is used very judiciously. "When we find parents who are in severe financial difficulty we go to the crisis fund," says Sokol. It might be to provide formula, which for special babies can run $6 to $8 per can. It might pay for insulin and syringes for a diabetic baby. Recently the crisis fund was dipped into to help provide cleft palate surgery for a three-year old girl. Other help came from area Kiwanis clubs and a surgeon who donated his time.

The Project ABC offices are housed at Santa Rosa Children's Hospital, but are not funded by the hospital. At its inception, the model project received a grant from the Texas Developmental Disabilities Program. But because it was funded as a unique model, the funds had a three-year time limit, and the three years end in 1984.

Since its beginning, other sources have been found, but they are never enough. Some money comes from the Hogg Foundation for Mental Health in Austin, but that money also terminates in 1984. The city of San Antonio supports the project, and after a long battle it was recognized as a United Way Agency.

"But," says Sokol, "what we need more than anything right now is money on which to operate." She is not above doing whatever she can in that effort. Last spring she called Rabbi Harold Kishner, author of "When Bad Things Happen to Good People," and asked him to come to San Antonio to speak. Proceeds from the benefit went to enhance the crisis fund. "I can't believe I had the nerve to do that—just call him up," chuckles Sokol.

And, also recently, Humana Women's Hospital asked Project ABC to run its gift shop and funnel profits into the Project's budget. Humana donated the space and gave the project an interest-free loan to purchase inventory for the shop.

In Sokol's word, Project ABC has simply "mushroomed." "None of us knew the need was so great in the beginning," says Sokol. "And I worry about how we will keep going—but I know we can't stop." So she continues to pass out literature and make phone calls and hope that people will hear and respond. Because Project ABC believes that Any Baby Can, and every baby deserves the chance to be the best that he can be.

MARY C. CERRETO, Ph.D.
Assoc. Professor of Pediatrics
Pediatric Psychology
Univ. of Texas Medical Branch
GALVESTON, TEXAS 77550

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EDITORS:	Beth A. Fine, MS Natalie W. Paul
ASSISTANT EDITORS:	Florence Dickman Elizabeth O'Brien Eakin Sue Conde Greene

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Sibs of Children With Chronic Conditions: Counseling Considerations*

Mary C. Cerreto, PhD

Child Development Division, Department of Pediatrics, University of Texas Medical Branch, Galveston, TX 77550

The families of handicapped and chronically ill children are receiving increased attention from health professionals. The benefits of treating the child within a family context go hand in hand with a recognition of the family as the child's primary interaction environment and the crucial social institution for child development. It is generally recognized that the child is best served by working with the family and that parental involvement is critical to therapeutic effectiveness. Reports and studies of the "handicapped family," however, have been limited primarily to considerations of the parent and affected child in a variety of areas: informing the parents of diagnosis [1, 2]; counseling concerns [3–7]; characteristics of the parents [8–10]; impact of the child on the parents [11–15]; and educating the parents about handicaps [16, 17].

The brothers and sisters of handicapped and chronically ill children have been sorely neglected. Even those studies that address the impact of a handicapped child on the family make scant reference to the effects on normal sibs [18–22].

With the growing interest in the effects of a handicapped child on the family, a series of anecdotal and clinical reports have been published indicating that the normally developing brothers and sisters in these families may be at high risk for a variety of disorders. There now exists a small body of empirical literature addressing the impact of a handicapped child on the normally developing child and noting both the positive and negative effects of this impact. As a whole, these studies delineate the concerns of sibs and provide direction for counseling and other therapeutic intervention.

IMPACT ON SIBS

That the effects of having a handicapped sib are long-lasting and far-ranging is underscored by Cleveland and Miller [23], who studied the life commitments of adult normal sibs. A questionnaire was mailed to 194 adult

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older sibs of adult mentally retarded persons; 109 were returned and 90 analyzed. The oldest female sibs reported significantly more responsibility for the affected child while growing up and seeking significantly more professional counseling as adults than older brothers. Many more females reported entering careers in the helping professions of teaching, social work, and nursing. Only females reported lack of sufficient attention from parents and influences on their decisions to have children. Brothers reported significantly less knowledge than sisters of family discussions about placing the child outside the home, and less knowledge about mental retardation. More frequently they also reported being told nothing by parents and seeking genetic counseling before having children of their own. While other studies have looked at the adult sibs of handicapped persons (Grossman [24]), none has so clearly depicted the major adult life decisions made on the basis of growing up with a sib who had mental or physical problems. The Cleveland and Miller study [23] noted the impact upon major life areas of career and family planning. It also noted that effects may be very different depending upon the sex of the normal sib.

If we have some indication that the impact of having a handicapped sib lasts into adulthood and affects major areas of life, what do we know about the range and prevalence of the impact on the normal sibs during childhood and adolescence? Reports are varied, and few compare sibs of handicapped children with sibs of normally developing children. In a survey of sibs of children with congenital heart disease, Apley, Barbour, and Westmacott [25] report that 27% of the sibs had behavior problems, 13% had somatic disorders, and 24% displayed both types of problems. A study of the sibs of children with leukemia [26] found evidence of headaches, anxiety, school phobia, poor achievement, depression, and recurrent abdominal pain in approximately 50% of the children. Similar problems have been noted in the sibs of children with spina bifida [27], cystic fibrosis [28], mental retardation [29, 30], Down syndrome, and cleft palate [31].

The literature, however, is by no means uniform in reporting a higher number of adjustment problems in the sibs of handicapped children. Gath [31] found no significant differences in teachers' and parents' behavior problem checklist ratings of sibs of children with Down syndrome, cleft palate, and normally developing children ages 8 to 12. Other investigators have reported similar findings (ie, Gayton et al [32]; McHale et al [33]). In fact, McHale and her colleagues [33] found that children with handicapped sibs were perceived as *more* supportive and accepting and less hostile toward the handicapped child than sibs of nonhandicapped children. The children themselves also expressed similar feelings about their brothers and sisters. The integrative effect that a retarded child may have on the family has been noted by Robinson and Robinson [34].

FACTORS INFLUENCING ADJUSTMENT

The investigation of factors that influence the psychosocial adjustment of the sibs of children with chronic illnesses and handicaps has led to a search for those variables that may be manipulated to enhance the coping abilities of the children. For a complete review of these factors, the reader is referred to Simeonsson and McHale [35]. A large number of variables have been investigated and it is difficult to draw definitive conclusions. Additionally, for the most part, the variables that are reported repeatedly in the literature are stable characteristics of the sib, family, or handicapped child, characteristics such as age, sex, and socioeconomic status. While it will be important for counselors to be aware of the differential effects of such characteristics, these variables are not expected to change through intervention. Simeonsson and McHale [35] note several variables which have been shown to be consistently related to sib adjustment across a wide range of investigative situations and methodologies: socioeconomic status (SES), gender, birth order and family size, severity of handicap, and parental attitudes.

The relationship of SES to the adjustment of the normally developing sibs in the family has been noted even in the earliest of studies (eg, Farber [20]). Farber [20] investigated the effects of a severely retarded child on family integration and noted the differential effects dependent on the family's SES. He describes these effects in terms of the daily living patterns and value systems assumed to be associated with SES. Other investigators proceeded to study how the differential due to SES impacted in turn on sibs. Grossman [24] interviewed the college-age sibs of retarded children and noted that the problems of middle-class sibs appeared to be primarily those of the psychologic acceptance of the affected child; the adjustment of lower class sibs was more closely associated with objective characteristics of the handicapped child, especially in relation to the degree of daily care required. A major factor involved in the reactions of upper- and middle-class sibs is stigma and of lower-class sibs is "burden of care" for the affected child and is a recurrent theme in studies of the families of handicapped children [30].

These studies were uniform in noting that the female sibs were more strongly affected by the burdens of caretaking than were male sibs. More recent studies raise the question of an interaction effect between the sex of the sib and birth order. Both Breslau [36] and Lavigne and Ryan [37] in studies of sibs of children with congenital disabilities, leukemia, cardiac problems, and physical problems requiring plastic surgery reported significantly more adjustment problems in younger male sibs. That older sibs appear to be less affected by the presence of a handicapped child has also been reported by other investigators [24, 38].

It is clear that the relationship between age and birth order is a complex one that merits further investigation. The relationship may be very dependent on the developmental processes of both the children and the family. Since there is some indication that handicapped individuals increasingly disrupt family life as they grow older [38a, 39], the family stage at which the sibs are assessed may be an important intervening variable.

The severity of the child's handicap also can be expected to affect how well the sib adjusts to daily living with a child having a chronic condition. Although the body of the evidence indicates that sibs are more adversely affected by more severely handicapped brothers and sisters, such findings are confounded by other variables such as SES, family size, sex of sib and handicapped child, and parental attitudes. Systematic study of these variables and their relative contribution to the adjustment of sibs is warranted.

The literature on the psychosocial adjustment of sibs notes the influence that parental attitudes have on the sibs' acceptance of the handicapped child. Open communication about the child's handicap and the ability and/or willingness of the parents to convey positive attitudes about the handicapped child appear to be important variables in sib understanding and adjustment [29, 40–43]. The importance of the variables of parental attitudes is underscored because, as opposed to variables such as age, sex, and SES, it has the potential for change.

CONCERNS OF SIBS

Knowledge of those factors influencing sib adjustment is important to the planning of counseling support and/or intervention with the sibs of children with chronic conditions. Of equal import to the counselors are the concerns expressed by the sibs themselves. What are the issues that sibs see as most relevant to living with a handicapped child? While much of the information we have about sibs' concerns as derived from anecdotal clinical reports, these are consistent in the types of issues and problems expressed by sibs. Posed in the form of the questions sibs ask, these concerns are listed below:

1) "How do we deal with parents who do not or will not discuss the handicapping condition (eg, mental retardation, muscular dystrophy, spina bifida) in the family?" [43].
2) "What can my handicapped sibling do and what can't he do?" [44].
3) "How did chromosomes cause my sister to be handicapped?" [44].
4) "What is the future going to be like for my brother?" [44].
5) "How does my retarded sister understand what she has? How does she understand the world she lives in? What kinds of feelings does she have?" [45].
6) "Does my brother know right from wrong? Does he mean what he does?" [45].
7) "What will happen to my brother if my parents die?" [43].

8) "Why does my sister go to the doctor's so often?"
9) "What does the psychologist do with my brother when she takes him into that little room? What's in the box she carries?"
10) "My sister has the same parents and grandparents as I do. We have a lot of things in common. Does that mean I am going to have the same problems she does?" [23, 24, 45–47].

A primary need that sibs express is one for *knowledge* and *information*. The most common clinic procedure allows for conveying the diagnosis to parents. Under the most optimal of conditions conveying the diagnosis, and clearly and understandably conveying the etiology and ramifications of the condition are extremely difficult tasks even between adults. The assumption that parents can or will, at this very emotionally laden stage of their lives, go home and convey the information to brothers and sisters may be unfounded. Some parents may be embarrassed if their child has a condition such as mental retardation and may prefer only to tell the sibs that the child is "sick." Other parents may have a difficult time explaining complex disorders such as Duchenne muscular dystrophy in words that a child can understand.

The expressed need for information and knowledge has implications for clinic procedures and for the role of the counselor in working with the families of handicapped children. During the period when the diagnosis is conveyed to the parents and when initial questions are answered, clinic procedures should allow for time to be spent with the sibs, alone, or with the parents. The period directly before the diagnosis may have been a very busy time for the parents and the affected child, one filled with many diagnostic tests and appointments with a wide variety of professionals. The sib may be wondering already about what is going on and may be feeling neglected. Some "special time" with the health staff in the early stages of working with the family may prevent problems later.

The health staff may also need to help the parents convey information about the affected child's specific condition to the sibs. Few books have been written specifically to fill this need. Notable exceptions are *Becky's Story* by Baznik [48] and *The Sib Book: A Book about Facts and Feelings for Brothers and Sisters of Children with Special Needs* that is being developed by the SEAFAM Project at the University of Washington [49]. For the most part, however, the books and materials that are appropriate in the health education of the affected child are equally appropriate for the sibs. Many of these materials are available from associations formed in conjunction with specific conditions (eg. Epilepsy Foundation of America, Juvenile Diabetes Association, March of Dimes). The Association for the Care of Children's Health (3615 Wisconsin Avenue, N.W., Washington, D.C. 20016) distributes a listing of materials for children that cover a wide variety of chronic illnesses and handicapping conditions.

The same premises that cover conveying information to parents govern conveying information to sibs. Counselors need to be concerned about the *accuracy* of information conveyed, the *amount* of information conveyed at any given time, and the conceptual *level* of the information. For young children, the explanation may need to be very basic, giving only one or two points. Older children may want to know everything, including the genetics of the condition. At *no* age is it appropriate to give *incorrect* information. Care is also taken not to place blame on the child or any other person.

Another series of concerns of sibs revolves around their difficulties in *interacting* with their handicapped brother or sister:

1) "How do I manage my brother?" [43].
2) "Am I supposed to discipline my sister? How? How do I get her to do what I want her to do?" [45].

It is not surprising that sibs have questions about how to interact with their handicapped brothers and sisters. How to interact effectively with their handicapped children and how to enhance the performance of good behaviors and decrease the frequency of maladaptive behaviors are common concerns expressed by parents. Feelings of sadness, pity, or overprotectiveness often prevent parents from setting the limits their handicapped children need to differentiate acceptable from nonacceptable behavior. Yet parents, as parents, have clear responsibility for the discipline of their children. With sibs this responsibility is far less clear. Some of the immature or deviant behaviors of the affected child may make it even more difficult to develop effective methods of interaction with the child.

It is important for parents to convey to sibs their clear guidelines for child-child interactions in the family. While it can be assumed that praise and ignoring the handicapped child are interactions that most parents would permit between their children, the guidelines for punishment are less clear. The sibs must know for what behaviors, when, and under what conditions it is permissible for them to punish the affected child. The counselor can help both the parents and sibs to learn that physical punishment, like hitting, is not usually effective in teaching the child to stop or change the maladaptive behavior. They can be taught techniques like sitting the child in a chair or putting the child in his/her room for a short period of time.

The largest number of expressed concerns of sibs, however, appear to revolve around their ability to deal with their *feelings* and how to act in *social situations* involving their handicapped brother or sister.

1) "Why did this have to happen to me?" [43].
2) "How do I handle my hurt feelings when my friends show off all the things that their brothers and sisters can do, like play baseball, sing in the choir, or compete in math club—that mine can't?" [43].
3) "How do I convey to other people that I think living with my sister really has made me different in very positive ways?" (increased idealism and

humanitarianism [23, 29], more altruism and tolerance [24, 50–52], increased feelings of family cohesiveness, more shared empathy with people with problems, a greater understanding of the problems faced by handicapped people [53]).

4) "I keep feeling that I have to do extra things to 'make up for' what my brother can't do, like get better grades, or make the first string on the team" [23, 54].
5) "How do I explain to my friends about my sister's condition?" "How do I tell a date?" [43].
6) "How do I let my parents know that I really resent the amount of time they spend with him?" [37, 55].
7) "How do I let my parents know that I think it's unfair that I always have to babysit her?" [53].
8) "What do I do when other kids tease my brother?" [43].

Counselors can make parents aware that sibs of children with chronic conditions do have a wide variety of feelings. It is important for parents to know that their range of feelings is indeed wide—that some feelings are indeed very positive, and that others have negative ramifications for the development of the child and for family integration. In many situations, simply conveying this type of information is sufficient to elicit parents' behavior change. Parents may then find themselves listening to what the sibs say from the vantage point of new understanding. They may also make a concerted effort to enhance the child development of the normal sib by taking a new look at the distribution of household responsibilities and/or the sibs' extracurricular activities.

The sibs, too, can be helped to learn to more effectively approach parents, friends, and others in situations that involve their handicapped sib. Such an approach is described in the following section.

MODEL PROGRAM DEVELOPMENT

In response to those sibs' concerns that have been noted both in the literature and in clinical observation, the Department of Pediatrics at the University of Texas Medical Branch developed and implemented an organized program for the school-age (ages 8–12) sibs of children with handicaps [56] called *Skills for Special Sibs*. The following description provides a framework for similar sibs' programs in both educational and clinical settings.

Initiation Phase

It is wise to remember that sibs' programs are for the most part preventive measures. They are designed to help children better understand their own concerns about living with a handicapped child, and to develop a better set of emotional and social coping skills. Sibs' programs are often introduced to families without clear linkages between sib problems of life with a handicapped child. It has been noted that the verbal linkages are often not expressed by children themselves until the sibs reach adolescence and the stage of formal operational thought. On the whole, people appear to be more inclined to take action around problem situations rather than preventive ones; therefore, parents may be reticent to have the normally developing sibs participate in a group focused on the handicapped child. If parents see that things are proceeding smoothly in the family, they may be worried that a sibs' group will "create problems that are not there." They may express a desire to "let well enough alone." Life with a handicapped child, as life with any child, has its normal number of "ups" and "downs" and parents are also concerned that their normal sibs may be indiscrete about what they reveal concerning the family's private life. "Kids say the darndest things" is funny until one of those things is a personalized statement that may be wrongly interpreted by persons outside of the family. Other parents attempt to treat all their children equally and fairly, and are concerned that a sibs' group will only enhance the differences the sib sees between him/herself and the handicapped child. Parents are also concerned that their normal sibs may come home with questions that they are unprepared to answer. Questions such as "Why does my brother have slanted eyes?" "Does my sister know right from wrong?" "What is he going to be like when he grows up?" and "Who is going to take care of her when you get old?" are very difficult to answer when asked "out of the blue."

The initial stage in the preparation of a sibs' group is therefore the sensitive, considerate preparation of the parents. This includes an open and honest information exchange about what the sibs' group can be expected to do. The procedure utilized at the University of Texas Medical Branch involves an initial phone call to the parents and an initial family session for parents, sibs and handicapped children together. The initial family session has two goals. The first is to convey information about the sibs' group—its purpose, techniques, expectations, etc. The second is to engage the normal sibs in response to questions about life with a child who has mental or physical problems. The tone established is one of the "specialness" of the sibs of special children . . . with the understanding that sometimes it's "special good" and at other times it's "special not-so-good." Questions begin to set a positive tone: "What is the thing you like best about your brother?" They also set the stage for the future discussion of problems and concerns: "What's one thing that your sister does that you really don't like?" Other questions are aimed at interfamily relationships: "What's the most important thing you would like your parents to know about you?" "What would you like to know about your brother or sister?" The discussion that evolves from the initial family session is usually sufficient to alleviate many parental anxieties about their children's participation in the sibs' groups.

Parents are told that one of the purposes is to help the sib become a more informed and skilled person in relation to their handicapped brother or sister. Therefore, it is reasonable to expect that they will go home with questions that the parents may now know how to answer comfortably. In this event, the UTMB staff note that they are available to help the parents productively respond to their children's questions.

Program Development

The University of Texas Medical Branch siblings program, "Skills for Special Sibs: Learning to Live With Your Handicapped Brother or Sister," is theoretically based in the principles of the Social Learning Theory. It was designed to address the perceived needs of sibs to develop better behavioral skills, to interact with the handicapped child in the family, and to develop the recognition of their own feelings and the social skills that will enable them to most productively interact with friends, parents, and other persons in situations involving their handicapped brother or sister.

The sib-sib interaction component draws on the work of H. Miller [57] in systematic parent training. His parent training model was adapted to the cognitive level of 8 to 12-year-old children. Units in this section teach the children basic rules of Social Learning Theory (ie, that behavior is learned, that you can change people's behavior by the way you act), how to praise their sib, how to effectively ignore, and how to sit down and talk to someone about a problem.

The feelings and social skills component of the program draws on the work of A. Goldstein [58] in the teaching of social skills through Structured Learning Therapy. First, a short videotaped vignette is presented. The children in the taped situation *model* the learning points for that particular session. The sibs in the group then *role play* situations on the tape and are *socially reinforced* for the performance of the correct behaviors and illustration of the learning points. The counselor and the sibs suggest other similar situations to role play to enhance the *generalization* of learning from the group session to the natural environment. Situations in the second component of the program involve labeling and identifying emotions, preparing for a conversation, preparing for a stressful conversation, and handling anger.

Each vignette session incorporates children's statements that may be used as stimuli for further discussion. For example, in one vignette Ilana, who is in a wheelchair, looks at her sister and says, "Sometimes mom and dad don't think I can do many things because of *this*," as she hits the arm of her wheelchair. Counselors use such statements to help the sibs relate to similar issues in their own family. The variety of handicaps illustrated in the vignettes also form the basis for teaching facts about different chronic conditions of childhood including "visible" handicaps (eg, being in a wheelchair) and "invisible" handicaps (eg, having a learning disability).

A homework sheet provided at the end of each session provides a behavioral assignment to be done at home. It gives the child an opportunity to *practice* at home those skills learned in each session. Discussion of the homework assignment at the beginning of the following session provides the group leader with a task around which to *review* the learning points of the previous session and to lead into the topic for the current session.

A Children's Workbook contains a short introduction to each session and the learning points of the taped vignette. It contains activities for the children to complete during the session and the homework sheets. A Teacher's Manual contains the transcripts of each session's vignette, detailed instructions for conducting the sessions, and additional ideas for role play and discussion. Sessions can be conducted with individual sibs during clinic visits or with groups of four to eight in a variety of settings.

CONCLUSION

Being the sibling of a child with special needs has a very special meaning. Sometimes, this "specialness" is very positive and includes pride in such events as the child's performance in the Special Olympics, a week of good behavior in school, learning to drink from a cup independently, a family outing in the community. Those events that may be common to other families and often taken for granted are seen as joyous milestones in families who have a child with a handicap. Sibs express a greater understanding of people with a wide range of problems and see their own growth and development enhanced through the experiences of daily living with a child with problems.

There are other times, however, when this "specialness" may indeed have negative ramifications on the growth and development of the normal children in the family. The necessary time that is devoted to the care of a handicapped child may breed feelings of resentment, jealousy, and anger. Their own opportunities for peer socialization may be curtailed because of responsibilities of caring for the handicapped child at home.

Parents, counselors, and other health providers need to be acutely aware of the dual nature of children's experiences in daily living with a child who has mental or physical problems. Changes in clinic procedures can help the sibs to gain knowledge and understanding of the nature of the child's condition and help them feel they are an important part in planning for the child's future. Open, frank discussions and the skills training approach to helping sibs, deal with their emotions and situations with peers or adults involving the handicapped child will enhance their abilities to cope with their special circumstances. Only when we include the sibs in our therapeutic endeavors will we be able to say that we take a truly integrated "family approach" to fostering optimal development in the lives of children with handicaps.

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Health Care Access and Use Among Handicapped Students in Five Public School Systems

Judith D. Singer, Ph.D.
John A. Butler, Ed.D.
Judith S. Palfrey, M.D.

From Children's Hospital--Boston, Community Services Program

Running Head: Health Care for Handicapped Students

Address Correspondence About Manuscript To: Judith D. Singer, Ph.D., Harvard Graduate School of Education, 308 Larsen Hall, Cambridge, MA 02138 (617) 495-1961.

Address for Reprints: Judith D. Singer, Ph.D., Harvard Graduate School of Education, 308 Larsen Hall, Cambridge, MA 02138.

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ABSTRACT

We studied the health care access and utilization patterns for a stratified random sample of 1726 special education students in five large metropolitan school systems. Overall, 7 percent of the special education students had no regular source of care, 26 percent had no regular physician and 38 percent had not visited a physician in the previous year; 13 percent had no health insurance. Each of these measures was worse for non-white and poorer children as well as for those whose mothers who had less formal education. Insurance coverage was associated with the location of a regular source of care and physician visits, with 45 percent of the uninsured children visiting a physician, as compared to 63 percent of those with public insurance and 66 percent of those with private insurance. Odds ratios for all health care access and use measures showed striking geographic variations. Thus, even for children identified as handicapped by their communities, barriers to health care are evident and are significantly greater for groups traditionally at risk.

INTRODUCTION

Currently, 4.3 million children are receiving special services within the nation's schools because of physical, developmental or educational handicaps.[1] This group of children comprises approximately 11 percent of the elementary and secondary school population,[1] and is itself very heterogeneous, composed of youngsters who are "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired and (those who) have a specific learning disability."[2]

The health care needs of special education students are likewise diverse.[3] For many, the only major requirement is a periodic physical exam to assure both the parents and the school that no significant sensory, neurodevelopmental or metabolic problem entirely explains the child's difficulties. For others, however, including many of the mentally retarded and those with serious physical or chronic health disorders, more extensive medical involvement is required for the prescription, implementation and monitoring of therapies.

Health services for the entire group of special needs children have taken on particular saliency since 1975, with the enactment of the Education for All Handicapped Children Act (P.L. 94-142), which mandates that each child be educated in the "least restrictive environment" consistent with his or her needs.[1,4] Seriously handicapped and chronically ill children who would have been at home or in institutions fifteen years ago are now receiving educational service through public school auspices and many children with significant handicaps who would have been in special schools are now attending regular schools and classes alongside non-handicapped peers.[5]

P.L. 94-142 contains no explicit language about the provision of health care services to special needs children.[1,3] But numerous educational and medical groups, recognizing that adequate health care access and use can be prerequisite to school attendance and successful school performance, have joined forces to establish local, state and federal interagency agreements to coordinate and deliver services.[6,7] Anecdotal reports and individual project summaries point to the success of specific efforts.[8,9] To date, however, few investigations have provided basic descriptive information on the medical care of handicapped school-age children.

To examine the patterns of medical care access and use among handicapped children, the Collaborative Study of Children with Special Needs investigated the experiences of a probability sample of over 1700 children in five of the nation's largest school systems. This paper presents data on access to and use of health care according to study site, and child and family background characteristics.

METHODS

The Collaborative Study was conducted in five large urban school systems, selected for geographic, socioeconomic and ethnic diversity: Charlotte-Mecklenburg, North Carolina; Houston, Texas; Milwaukee, Wisconsin; Rochester, New York; and Santa Clara County, California. The community-based design was chosen over a national probability sample because such a design afforded the opportunity to obtain both nationally relevant information and detailed data on local health care and special education policies.

Sample. The sample was drawn using a stratified random selection technique to ensure adequate numbers of children with more severe but less common problems.[10] This method of sampling permits generalizations both for subgroups of children and for the special education population as a whole. In each site, the special education population of children in kindergarten through sixth grade was divided into three strata based upon the school's designation of primary handicapping condition: (1) those with speech impairments or learning disabilities; (2) those with emotional and behavioral problems or mental impairments; and (3) those with physical, sensory or health impairments. An initial sample of 3100 children was selected, divided approximately equally across the three strata and five sites.

From the initial sample, 273 children (9 percent) were ineligible to participate because they had moved out of the district, were no longer in special education, were siblings of others in the sample, or had died. Consent was granted for 2048 (72 percent of the eligible sample), from which a random sample of 1726 was selected for study. A comparison of the ineligible students with the remainder of the initial sample revealed that they were more likely to be speech impaired or learning disabled, but they did not differ significantly with regard to age, grade, sex, race, or ethnicity. A comparison of the refusing and consenting cases on these same measures revealed only one significant difference in one stratum and site, for which adjustment was made when sample weights were constructed.

Measurement. In the spring of 1983, parents were interviewed for 40 minutes over the telephone in either English or Spanish by personnel from the University of Illinois Survey Research Laboratory. Questions about health care access and use were based upon those used in the National Health Interview Survey[11] and the National Survey of Access to Medical Care.[12] Access was measured using four indicators: (1) whether the children had a regular source of care; (2) the location of this regular source; (3) whether they had a regular physician; and, (4) whether they were covered by a private or public health insurance plan. Use of medical care was classified into two types: (1) primary care, composed of services provided by general practitioners, pediatricians, internists and family practitioners; and, (2) specialty care, composed of services provided by all specialists not listed above, except psychiatrists.

The child's primary handicap was derived from the parent report of the child's "major handicapping condition or problem." For presentation, the population was divided into two clusters: those with "high prevalence" conditions including speech, learning, other developmental, hyperactivity, or emotional problems; and those with "low prevalence" conditions, including mental retardation, Down Syndrome, deafness, cerebral palsy, other neurological problems, or general medical problems. The child's race or ethnicity was derived from school records; family size, family income, and mother's education were asked during the parent interview. Based upon a family's size and income, its standing relative to the 1982 poverty line was computed.[13]

Statistical Analysis. Estimates presented in this paper are based on a weighting procedure which compensates statistically for the oversampling of low-prevalence disability groups in the sample. Within each site, weights were computed to generalize the results to the special education population of that site. These weights were then calibrated to total the actual number of respondents in that site, so that estimates across school systems reflect an approximate average of the individual site results. Estimated standard errors of percentages, presented in the Appendix, also were computed taking the sampling design into account.

The total sample size of 1726 is large enough to provide ample statistical power (greater than .80) to detect small effects.[14] Within subgroups power does diminish, but as shown in the Appendix, estimated standard errors remain relatively small.

Constraints on Inference. Although each of the five samples is a representative probability sample of that district, their combined results cannot be expected to generalize to all school districts across the country. In particular, the focus on major metropolitan areas means that, at best, the findings may be reflective of national urban experience, but not small-city or rural experience. Also, because the data in the study are cross-sectional, direct causal inferences are not warranted. However, various statistically significant associations are described and considered from both statistical and practical points of view.

RESULTS

Table 1 shows selected background characteristics of the study sites with comparable national data if available. Taken together, the five communities encompassed a broad range of economic circumstances: Rochester and Milwaukee were relatively poor communities spending higher than average amounts on education while Charlotte and Houston had the converse pattern of being somewhat more affluent and spending lower than average amounts on education. Santa Clara County, representing a third pattern, was the most affluent district, spending average amounts on schools. The percentage of elementary school students in special education likewise spanned a wide spectrum from 8 percent in Charlotte and Houston to 13 percent in Rochester. Each site had a substantial minority population, comprising at least 40 percent of all elementary school students. In all sites but Santa Clara, Blacks were the predominant minority; Houston and Santa Clara had large numbers of hispanics as well.

Regular Source of Care, Location of Care and Regular Physican. Ninety-three percent of all special education students had a regular source of care (Table 2). This percentage was identical to the national average of 93 percent for all 6 to 17 year olds as reported in the 1982 National Survey of Access to Medical Care.[15] As previous surveys have found, however, health care access differed by geographic location and child and family background characteristics.[12,16,17]

The proportion of children without a regular source of care varied seven-fold, from 2 to 15 percent, across the five communities studied. Houston and Charlotte reported the lowest percentages of children without a regular care source (15 and 12 percent respectively), while both Santa Clara and Rochester had almost total access, with 98 percent of each site's population reporting such a source.

Black and hispanic children were two and three times as likely as white children not to have a regular source of care. Poverty status and mother's education also were strong predictors. While the trend for mother's education was linear, with higher maternal education associated with an increased likelihood of the child's having a regular care source, the trend for poverty status reflected the "U-shaped" distribution that has come to be associated with children's access to health care since the implementation of Medicaid:[18,19] Those living between 100% and 200% of the poverty line were less likely to have a regular source than either those living above 200% of poverty or those living in poverty. In addition, children with high prevalence handicaps were over twice as likely as those with low prevalence handicaps not to have a regular care source.

The comparability between the special education population and the general urban school-age population ends when the configuration of care sources is considered: Only 63 percent of the special education students received their care in private offices as compared with 84 percent in the general population as reported in the 1982 Access Survey.[15] The balance of care for special education students was provided in hospital clinics and outpatient departments (19 percent), other clinics and neighborhood health centers (8 percent), and emergency rooms (3 percent). Sociodemographic variations similar to those for regular care source also were found: those children who were white, not poor, or who had better educated mothers were more likely to use private offices than those who were black, hispanic, less affluent, or whose mothers had less education. Rochester displayed a configuration of care sources significantly different than the other four sites, having the lowest percentage of children using private offices (48 percent) and the highest percentage of children using other clinics (22 percent).

When parents of the special education students were asked whether their child had a regular physician, approximately one-quarter said "no." The proportion was significantly higher--often in excess of one-third--among the same groups with a higher likelihood of not having a regular source of care: blacks, hispanics, the poor, those with high prevalence handicaps, those with mothers who were not high school graduates, and those living in Charlotte and Houston. No "U-shaped" distribution by the family's standing relative to the poverty line was found--the poorer the child's family, the less likely it was that the child had a regular physician.

Because study site is such a strong predictor of health care access and is associated with different socioeconomic, racial and ethnic distributions, the question arises whether differential access to health care persists within the individual communities. Table 3 permits a closer look at this issue, using the availability of a regular physician as the illustrative measure of access. Adjusting for study site, sociodemographic differences remain: non-whites, poor, near poor and low income children, and those with high prevalence conditions or poorly educated mothers were all at least twice as unlikely as their relevant comparison group to have had a regular physician. The one site where this pattern was broken was Rochester, in which the general sociodemographic differences observed across the sample were not statistically significant predictors. While individual sites may have more or less severe inequities, the general pattern of differential access to health care remains.

Health Insurance Coverage. Table 4 displays data on health insurance coverage by study site and child and family background characteristics. In the aggregate, 56 percent of the students were covered by a private plan, 32 percent by a public plan, and 12 percent had no health insurance at all. As with the other access measures, however, significant differences in both the likelihood of coverage and the type of plan were found by sociodemographic characteristics.

Across the five communities, the percentage of students without any health insurance varied four-fold, from 7 percent in Santa Clara and Rochester to 27 percent in Houston. The sites also varied in the type of insurance available to the majority of its children: public insurance was the modal coverage in Rochester and Milwaukee while private coverage predominated in the remaining three sites.

Racial and ethnic differences also were found--only 8 percent of white children were uninsured as compared to 12 percent of blacks and 26 percent of hispanics. The relative narrowness of the gap between black and white children is due in large part to public coverage--50 percent of the black special education students were covered by Medicaid, Title V, Crippled Children's or some other public insurance plan. Hispanics, in contrast, were far less likely than whites to have had private coverage, yet were equally likely to have had public coverage, thus producing the three-fold difference in likelihood of any coverage.

Comparison by poverty status showed roughly similar proportions of uninsured children among all but the not poor, who were at least four times less likely to be without coverage than those at other income levels. The relatively equal likelihood of coverage among less affluent groups can be attributed to a large extent to Medicaid, and a lesser extent to Title V, Crippled Children's and other public plans. Taken together, public sources insured 67 percent of the poor, 35 percent of the near poor and 21 percent of the low income children.

Was insurance coverage associated with having a regular source of care, a particular care setting, and a regular physician? Data presented in Table 5 show that among students with no health insurance, 20 percent had no regular source of care and 44 percent had no regular physician. Among those who were insured, those with public coverage were as likely as those with private coverage to have had a regular source of care (96 versus 98 percent), but were more likely to use hospital or other clinics (45 versus 20 percent) and less likely to use private doctor's offices (48 versus 73 percent).

Physician Visits. Identification of a regular care source, a regular physician and an insurance source does not necessarily guarantee that a child will visit the doctor. Table 6 presents the proportions of students with primary and specialty care visits in the last year as well as the proportions with no physician visit at all. Overall, 56 percent of the students had seen a primary care provider and 15 percent had seen a specialist, while 38 percent had not seen any type of physician. As with the access measures, however, subgroup differences were large.

The proportion of children not seeing a physician in the last year varied almost three-fold across the five communities studied, from 20 percent in Santa Clara to 56 percent in Houston, with the bulk of the difference found in the use of primary care. Only 36 percent of the special education students in Houston had been to see a primary care provider in the last year, as compared to 76 percent of the students in Santa Clara County.

Minority children were less likely than white children to have seen either a primary or specialty care physician. Considering both types of visits, only 48 percent of hispanic children and 51 percent of black children had seen any physician as compared to 79 percent of white children. Poverty status and mother's education also were strong predictors; in general, higher incomes and more education were associated with increased use. With respect to income, however, a "U-shaped" distribution was once again found, revealing that near poor and low income children were less likely to have seen a primary care provider in the last year than were their poorer or more affluent peers.

Differences among children according to their primary handicapping condition were found for both measures, with the gap far more pronounced for specialty care than for primary care. Those with low prevalence conditions were almost three times as likely as those with high prevalence conditions to have seen a specialist in the last year (30 versus 11 percent). Even among those with the low prevalence conditions, however, 25 percent had not seen any physician during the year.

Controlling for study site, sociodemographic differences and health care access persisted in all but one of the communities studied. Table 7 displays similar information for health care use--the percentage of children without a primary care visit in the last year by child and family background characteristics in each of the five sites. Adjusting for study site, sociodemographic differences not only remained, but in some cases were further highlighted: non-whites, poor, near poor and low income children and those with poorly educated mothers were two to three times as likely as their relevant comparison groups not to have seen a primary care provider in the last year. Moreover, subgroup differences, especially those by race and ethnicity, persisted in all five sites--even those that had made great strides towards equalizing access across groups.

Sociodemographic differences in utilization were found in all sites regardless of the degree of access. However, the data of Table 8 show that for individual children, access was a strong predictor of use. Among those using doctor's offices, 71 percent of the children had been to see a physician, as compared to 51 percent of those using hospital clinics, 57 percent of those using other clinics, and only 25 percent of those without a regular source of care. Children who had a regular physician were twice as likely as those who did not to use both primary care and specialty care. Similarly, children who were insured under either a private or a public plan were twice as likely as those who were uninsured to visit either type of physician.

DISCUSSION

This study examined health care access and use among children identified by the public schools as handicapped and in need of special education. Although the special education mandates do not regulate health care delivery procedures, there has been a presumption that children with educational disabilities deserve those health services that may enhance their ability to receive a free appropriate public education. The data from this study suggest that the health care pattern for children in special education is greatly influenced by the city and state in which they live, their race or ethnicity, and their socioeconomic background. Participation in special education does not necessarily guarantee improved access to or use of health care.

The overriding factor associated with the children's health care access was largely beyond their control--the city in which they lived. Across the five communities studied, the availability of a regular source of care varied seven-fold, insurance coverage varied four-fold and the availability of a regular physician varied over two-fold. Study sites with the poorest access--Houston and Charlotte--were those with the most stringent eligibility requirements for Medicaid and the weakest infrastructure of public clinics and neighborhood health centers. As evidence of a service model that is working in the face of tremendous obstacles, Rochester, NY, the poorest community studied, attained a proportion of children with a regular source of care, a regular physician and a source of insurance coverage equal to that of Santa Clara County, CA, the most affluent community studied. As evidence of what remains to be done, Houston, TX, a community with an above average per-capita income, had 15 percent of its special education students without a regular source of care, 27 percent uninsured, 37 percent without a regular source of care and 56 percent not having seen a physician in the past year. In contrast to the uniform national standards for the educational rights of children with disabilities, there are no uniform standards for their or their non-handicapped peers' health care rights.

Differential health care patterns for white and non-white children in all communities were clear. Black children were at least twice, and sometimes three times, as likely as white children not to have a regular source of care, not to use a private physician's office, not to have a regular physician and not to see a physician during the year. Due in large part to Medicaid, the gap in insurance coverage between these two groups has narrowed--blacks were uninsured only slightly more often than whites. Hispanic children, however, are even further removed from the health care system. In comparison to white children, they were over three times as likely not to have a regular source of care, not to have a regular physician and not to have insurance coverage; in addition, they were over twice as likely not to have seen a physician in the last year. Equality of access by racial or ethnic background has yet to be achieved, even for handicapped children.

Poverty also differentiated the special education population, with the more affluent children generally having an ongoing relationship with a particular physician, usually office-based, whom they were very likely to see at least once during the year. Poor, near poor and low income children, in contrast, were less likely to have or use a regular physician, and often relied on hospital outpatient clinics or neighborhood health centers. Medicaid has changed the relationship between poverty and health care for children, however. Children living below national poverty levels were more likely to have a regular source of care and use a physician than were their peers living between 100% and 200% of poverty.

Less striking than the racial, ethnic and income differences, a child's handicap was nevertheless a significant predictor of access to and use of health care. Children with the high prevalence handicaps--those with speech, learning, other developmental, hyperactivity or emotional problems--were only half as likely as those with the less prevalent conditions to have a regular source of care, to identify a regular physician and to visit a physician during the year. Children with high prevalence conditions represent the bulk of those receiving special education (over 70 percent of the group as a whole); thus, the differential in access and use affects large numbers of children. Although there is still some controversy among physicians and educators about the extent of involvement that health providers should have with these children, many developmentalists argue that those with speech and language problems should have periodic hearing and ear exams and that those with learning problems (particularly those with attentional or activity level problems) should have routine physical assessments including a thorough history, sneurological assessment and sensory exam. Even for those children whose need of regular health care is less controversial—those with the low prevalence conditions including mental retardation, Down Syndrome, cerebral palsy, other neurological problems and general medical conditions—use is less than perfect, with 25 percent not seeing a physician during the year.

The present study also demonstrates an association between insurance coverage and the availability of a regular source of care and a regular physician, as well as a relationship between all three of these access factors and the use of care. Although a causal link cannot be established with cross-sectional data, this does suggest that lack of insurance may be a major obstacle interfering with the use of health services for those not linked to the system or who are unable to pay.

How important are the findings on whether children have a regular physician? Having a regular physician and visiting him periodically may not be particularly valued by some families. Remembering the name of a physician and requesting a return appointment to that person may take second place to obtaining a visit at a time which can be managed within a demanding home and work schedule. Moreover, distrust of professionals may lead some families to desire anonymity. The small number of physicians from minority backgrounds also may be a factor, as may the traditional hospital out-patient or dispensary model with long waits and dependence on trainees. If these factors do contribute to the inequities, policy implications are clear: better education of patients about the importance of continuity of care, attention to designing clinics that can meet the needs of working parents, recruitment of minority health professionals, and the establishment of longitudinal training experiences which encourage residents and fellows to follow their patients over the entire two or three years of their training and to identify for their patients a staff member who will be available to them over the longer term.

Continued attention to the health care needs of special education students should probably take place in the context of improved access and use for all children. But the patterns found in this study suggest that even for the children society considers disabled, inequities continue in the provision of insurance coverage, availability of a health care facility and establishment of a continuing care relationship.

Table 1: Sociodemographic Characteristics of the Study Sites

Study Site	Characteristic					
	1979 Per Capita Income	1982 Per Pupil Expenditure	% Elementary School Students in Special Education	Race/Ethnicity[a]		
				% White	% Black	% Hispanic
Rochester, NY	$ 6,492	$ 4,228	13	37	49	11
Milwaukee, WI	7,104	4,242	11	38	51	8
Charlotte, NC	7,814	2,570	8	57	41	0
Houston, TX	8,857	2,696	8	19	43	35
Santa Clara County, CA	9,545	3,080	9	58	4	26
NATIONAL AVERAGE	7,330	2,913	11	b	b	b

a. Totals may not add to 100% because of students of other races or ethnic backgrounds.

b. No comparable data available.

[illegible] Regular
Physician by Study Site and Child and Family Background Characteristics.

Characteristic	Regular Source of Care: No	Regular Source of Care: Yes	Location of Regular Source: Doctor's Office	Location of Regular Source: Hospital Clinic	Location of Regular Source: Other Clinic	Location of Regular Source: ER	Regular Physician: No	Regular Physician: Yes
ALL SPECIAL EDUCATION STUDENTS	7	93	63	19	8	3	26	74
Study Site								
Santa Clara County	2	98	85	9	5	0	14	86
Rochester	2	98	48	25	22	2	14	86
Milwaukee	5	95	59	29	3	3	27	73
Charlotte	12	88	63	16	6	4	37	63
Houston	15	85	58	17	6	3	37	63
Race/Ethnicity								
White	4	96	81	11	3	0	12	88
Black	8	92	47	29	12	5	36	64
Hispanic	13	87	59	13	13	1	35	65
Poverty Status								
Poor	7	93	42	32	15	3	34	66
Near Poor	9	91	55	24	9	3	27	73
Low Income	10	90	65	17	6	2	26	74
Not Poor	4	96	84	8	4	1	14	86
Mother's Education								
Non-High School Graduate	9	91	48	27	13	3	32	68
High School Graduate	6	94	68	16	7	2	23	77
More than High School	3	97	83	10	2	1	11	89
Student Handicap								
High Prevalence Condition	8	92	61	19	9	3	28	72
Low Prevalence Condition	3	97	70	19	7	2	14	86

Table 3: Odds of Not Identifying a Regular Physician by Selected Demographic Characteristics within Study Sites

Demographic Characteristic	Santa Clara, CA	Rochester, NY	Milwaukee, WI	Charlotte, NC	Houston, TX	Adjusted Odds Ratio (95% Confidence Interval)
	STUDY SITE					
	(percent with no regular physician)					
Race/Ethnicity						
Non-White	22	16	36	49	43	3.6***
White	9	10	13	17	15	(2.7, 418)
Simple Odds Ratio	3.0***	1.7	3.6***	4.6***	4.4***	
Poverty Status						
Poor, Near Poor, Low Income	19	13	27	46	44	2.7***
Not Poor	11	16	15	17	14	(2.0, 3.7)
Simple Odds Ratio	1.9	0.8	2.0*	4.2***	4.6***	
Mother's Education						
Non-High School Graduate	24	13	33	47	46	2.3***
High School Graduate	11	10	19	27	28	(1.8, 2.9)
Simple Odds Ratio	2.5**	1.3	2.1**	2.5***	2.2***	
Student Handicap						
High Prevalence Conditions	16	15	28	39	43	2.3***
Low Prevalence Conditions	8	9	19	25	13	(1.8, 3.0)
Simple Odds Ratio	2.2	1.9	1.6	1.9	4.8***	

* $p < .05$
** $p < .01$
*** $p < .001$

Table 4: Health Insurance Coverage by Study Site, Child and Family Background Characteristics.

	Type of Insurance Coverage[a]		
Characteristic	None	Public	Private
ALL SPECIAL EDUCATION STUDENTS	12	32	56
Study Site			
Santa Clara County	7	14	79
Rochester	7	52	44
Milwaukee	8	52	41
Charlotte	12	25	62
Houston	27	18	56
Race/Ethnicity			
White	8	19	74
Black	12	50	40
Hispanic	26	20	55
Poverty Status			
Poor	16	67	19
Near Poor	16	35	51
Low Income	18	21	63
Not Poor	4	7	89
Mother's Education			
Non-High School Graduate	20	44	37
High School Graduate	8	26	68
More than High School	4	18	78
Student Handicap			
High Prevalence Condition	12	31	57
Low Prevalence Condition	11	37	55

[a] Percents may add across to more than 100% because a student may have both private and public health insurance coverage.

Table 5: Location of Regular Source of Care and Availability of a Regular Physician by Health Insurance

Insurance Coverage	Location of Regular Source of Care					Percent Without a Regular Physician
	Doctor's Office	Hospital Clinic	Other Clinic	Emergency Room	No Facility	
	(percent reporting care location)					
None	52	18	5	5	20	44
Public	48	32	13	3	4	27
Private	73	13	7	2	6	21

Table 6: Use of Primary and Specialty Care Physicians by Study Site and Child and Family Background Characteristics.

Characteristics	Primary Care[a]	Specialty Care[b]	No Physician Visit
ALL SPECIAL EDUCATION STUDENTS	56	15	38
Study Site			
Santa Clara County	76	19	20
Rochester	63	9	34
Milwaukee	60	15	35
Charlotte	45	17	45
Houston	36	13	56
Race/Ethnicity			
White	74	21	21
Black	46	9	49
Hispanic	41	13	52
Poverty Status			
Poor	51	9	45
Near Poor	45	10	50
Low Income	49	16	43
Not Poor	72	21	21
Mother's Education			
Non-High School Graduate	45	9	50
High School Graduate	59	17	34
More than High School	73	21	21
Student Handicap			
High Prevalence Conditions	54	11	41
Low Prevalence Conditions	66	30	25

NOTE: Percents may add across to more than 100% because a student may have seen both a primary care provider and a specialist in the last year.

a. Includes general practitioners, pediatricians, internists and family practitioners.

b. Includes all specialists not listed in (a), except psychiatrists.

Demographic Characteristic	Study Site					Adjusted Odds Ratio (95% Confidence Interval)
	Santa Clara, CA	Rochester, NY	Milwaukee, WI	Charlotte, NC	Houston, TX	
	(percent with no primary care visit in last year)					
Race/Ethnicity						
White	16	28	28	36	32	3.0***
Non-White	37	42	48	67	72	(2.4, 3.7)
Simple Odds Ratio	3.2***	1.9**	2.3***	3.7***	5.2***	
Poverty Status						
Poor, Near Poor, Low Income	37	39	42	65	73	2.6***
Not Poor	15	25	30	33	47	(2.0, 3.3)
Simple Odds Ratio	3.2***	1.9*	1.7	3.9***	3.0***	
Mother's Education						
Non-High School Graduate	44	44	41	69	73	2.3***
High School Graduate	19	26	39	45	57	(1.8, 2.8)
Simple Odds Ratio	3.4***	2.3***	1.1	2.7***	2.0**	
Student Handicap						
High Prevalence Conditions	24	38	42	59	66	1.7***
Low Prevalence Conditions	26	32	30	32	51	(1.4, 2.1)
Simple Odds Ratio	0.8	1.3	1.7	3.1***	2.0**	

* $p < .05$
** $p < .01$
*** $p < .001$

Table 8: Use of Primary and Specialty Care Physicians by Location of Regular Source of Care, Availability of a Regular Physician and Health Insurance Coverage

Access Measure	Primary Care	Specialty Care	No Physician Visit
Location of Regular Source of Care			
Doctor's Office	65	18	29
Hospital Clinic	44	11	49
Other Clinic	55	3	43
Emergency Room	26	3	73
No Facility	15	9	76
Regular Physician			
No	30	9	63
Yes	65	17	30
Health Insurance Coverage			
None	35	10	58
Public	58	12	37
Private	60	18	34

ACKNOWLEDGEMENTS

The authors wish to thank the special education departments of the participating school systems. In addition, we are grateful to Dr. Julius Richmond, Dr. Beatrice Hamburg, Dr. William Kessen, Dr. Edwin Martin and Gilbert Steiner for their consultation and advice.

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APPENDIX

The stratified random selection technique necessitates the use of a specialized formula for calculating standard errors of estimates.[10] Estimated errors for the percentages 10, 30, 50, 70, and 90 are presented in Table A for estimates based upon the full sample of 1726 and selected subgroups.

Table A: Estimated Standard Errors of Percents.

Characteristic	Sample Size	Percent		
		10 or 90	30 or 70	50
		(estimated standard error)		
ALL SPECIAL EDUCATION STUDENTS	1726	1.0	1.5	1.6
STUDY SITE				
Santa Clara County	347	2.7	4.1	4.4
Rochester	333	1.8	2.8	3.1
Milwaukee	355	2.0	3.1	3.3
Charlotte	351	1.9	3.0	3.2
Houston	340	2.4	3.6	3.9
Race/Ethnicity				
White	755	1.7	2.6	2.8
Black	678	3.2	5.0	5.4
Hispanic	251	2.6	4.0	4.4
Poverty Status				
Poor	397	2.9	4.4	4.8
Near Poor	315	2.3	3.5	3.8
Low Income	268	2.8	4.2	4.6
Not Poor	586	1.8	2.7	3.0
Mother's Education				
Non-High School Graduate	614	1.8	2.7	3.0
High School Graduate	585	1.7	2.5	2.8
More than High School	419	2.3	3.5	3.9
Student Handicap				
High Prevalence Condition	931	1.1	1.7	1.8
Low Prevalence Condition	792	3.0	4.6	5.0

**CAROLINA INSTITUTE FOR RESEARCH
ON EARLY EDUCATION FOR THE HANDICAPPED**
Frank Porter Graham Child Development Center
301 NCNB Plaza 322A
Chapel Hill, N.C. 27514 - (919) 962-2001

April 10, 1985

Select Committee on Children,
Youth and Families
Room 385, House Annex 2
Washington, D.C. 20515

Enclosed are some materials that may be of interest to you. The Marital Dissolution data enclosed (separation and divorce in families of young (birth to 5) handicapped children) are for 399 autistic children, but I have similar data on 1050 children with a variety of other handicaps. The stress of having a handicapped child is real. The need for early services is also real.

The green pages marked indicate the results of a survey done of state departments of Health, Education, Mental Health, Mental Retardation/DD, and Social Services in eight randomly selected states. Our results indicate that present social policies are better at substituting for families of handicapped children than at supporting them. This results in needless institutionalization of handicapped children at tremendous emotional and economic cost to families and taxpayers.

The need for respite care and other services is highlighted in A Family Focus for Intervention (p. 151), as is the comparison of high stress/low stress families. This chapter also includes information on fathers and siblings. The Developmental Perspective shows family service needs as the children grow older (pp. 113, 129) and also tells about the reduced rate of institutionalization found for a family-centered program (p. 132). The Support for Families paper identifies the most important sources of support for 150 parents. Hope some of this is helpful to you.

I've also enclosed a list of some recent publications from our project. If you'd like any reprints, just let me know.

Thank you for your efforts on behalf of families of handicapped children. Let me know if there is anything else I can do to help.

Sincerely,

Marie M. Bristol, Ph.D.
Senior Investigator
Research Assistant Professor
Division TEACCH, Department of Psychiatry

Enclosures
MMB/jmc

The Frank Porter Graham Child Development Center is a division of the Child Development Institute
The University of North Carolina at Chapel Hill

Marital Dissolution in Families of Young Handicapped and Nonhandicapped Children

M. M. Bristol, R. McConnaughey, E. Schopler

Handicapped Children's Early Education Program Conference
Washington, D.C.
December, 1984

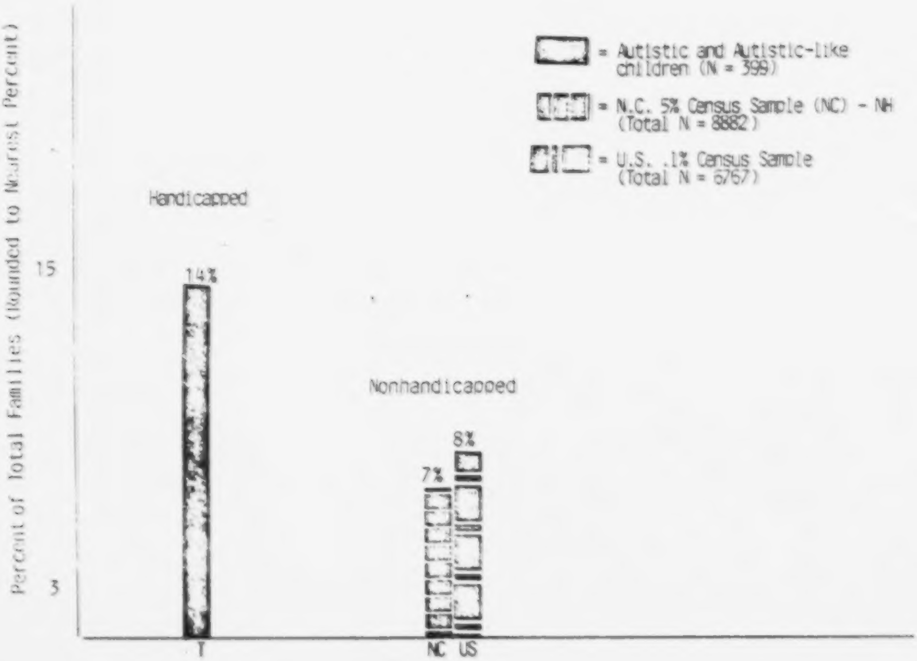

Figure 1. Marital Dissolution (Separation & Divorce) in Families of Handicapped and Nonhandicapped Young (< 6) Children.

Bristol, McConnaughey & Schopler, 1984

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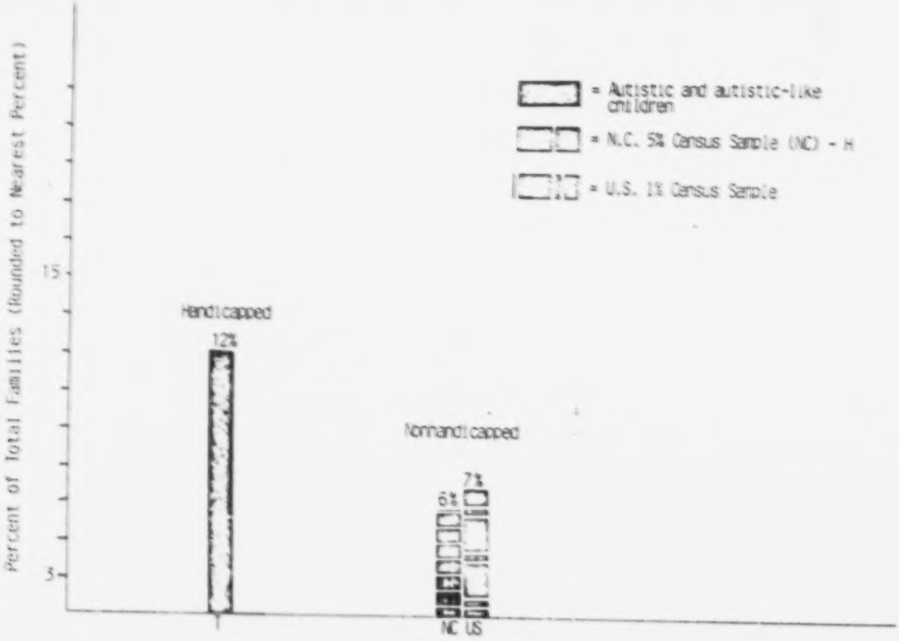

Figure 2. Marital Dissolution (Separated and Divorced) in Caucasian Families of Young (<6) Handicapped and Nonhandicapped Children

Bristol, McConnaughey, & Schopler, 1984

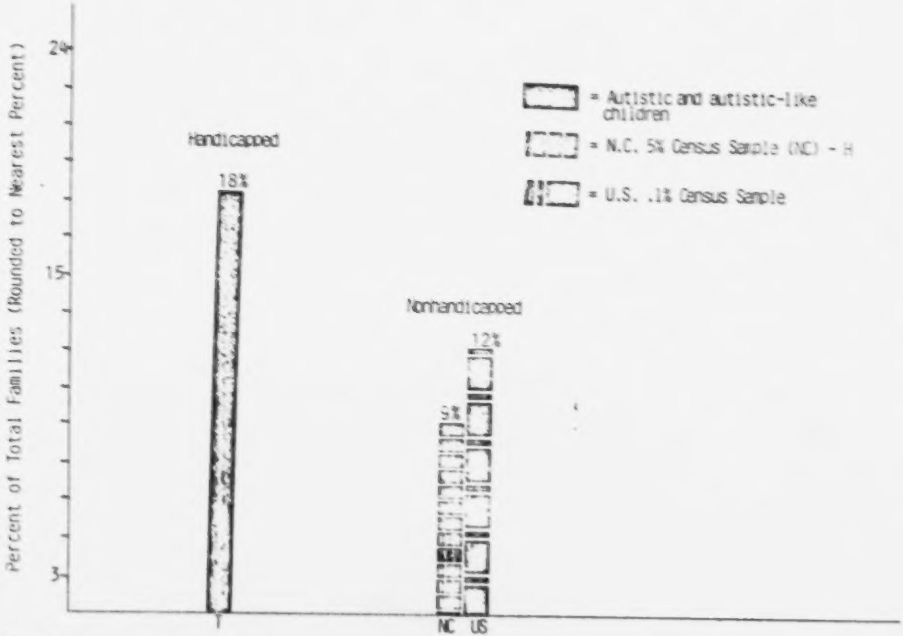

Figure 3. Marital Dissolution (Separation or Divorce) in Black Families of Young Handicapped and Nonhandicapped Children

Bristol, McConnaughey, & Schopler, [illegible]

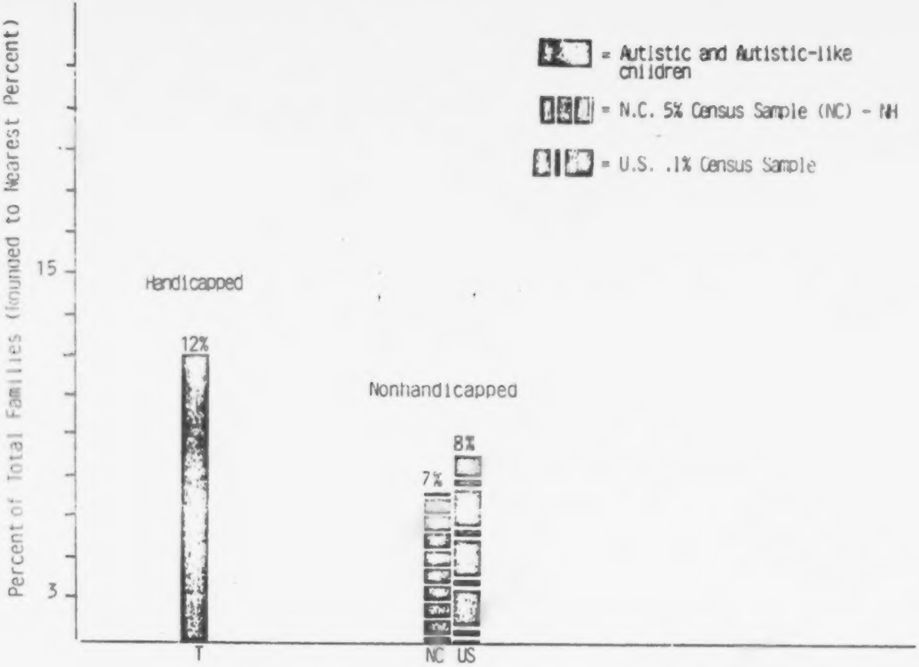

Figure 4. Marital Dissolution (Separation & Divorce) in Families of Handicapped and Nonhandicapped Young (< 6) Children (Firstborn Handicapped Only)

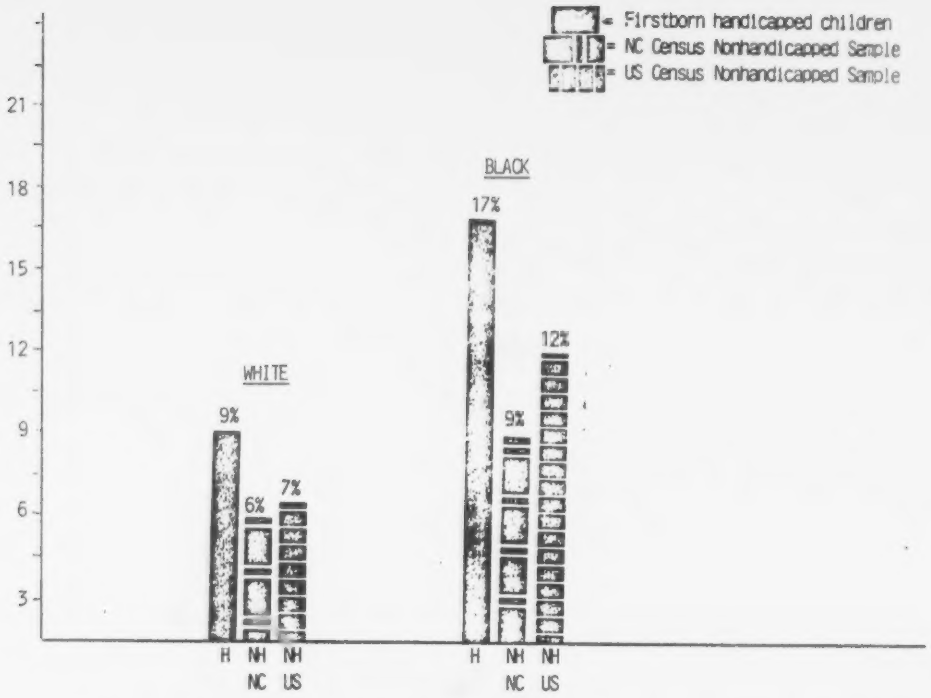

Figure 5. Marital Dissolution in Families of Handicapped and Nonhandicapped Young Children with All Children in All Families < 6.

Paper presented at the International Conference of the National Society for Autistic Children. June, 1982. Boston, MA.

Work With Families

SUPPORT FOR FAMILIES OF AUTISTIC AND AUTISTIC-LIKE CHILDREN

By

Marie M. Bristol
Division TEACCH
Department of Psychiatry
University of North Carolina
Chapel Hill, North Carolina 27514

As part of the TEACCH program (Treatment and Education of Autistic and related Communication handicapped CHildren), Eric Schopler and I are looking at the impact of autistic children on their families, trying to come up with answers to two questions. First, what information could we collect when we first meet a family that would help us predict which families are really hurting, which may be most in need of assistance? No matter how skilled and dedicated you are, if you're in a service program, the bodies are piling up at the door. There are 24 hours in a day and 36 hours' worth of work. There's the phone call you didn't make, the home visit you didn't get around to today, the letter that you're going to write tomorrow. We're trying to see if we can identify the families most at risk. The people that, no matter how busy we are, we've got to reach now.

The second question that we're asking is in which families are making it and why? For example, some studies show that in families of retarded children the divorce rate may be three times the national average and the suicide rate twice as high as average. But other families report that their marriages are stronger because of the handicapped child, that they feel there is a shared purpose in life that wasn't there before. I don't mean that these people are never defeated, never overwhelmed, never feel like giving up, but somehow they spring back while other families are simply overwhelmed by the stress. We want to know what differentiates these two groups of families.

Our initial study assessed 40 mothers of autistic children. Of these 40, we compared the highest stress group, (top quartile, 10 mothers) and the lowest stress group (bottom quartile, 10 mothers). Both groups were comparable in terms of family income, mother's age, number of children in the family, and number of mothers working outside the home. All children in both groups of families had been diagnosed as autistic and both groups had comparable percentages of severely and mildly autistic children. Yet one of these groups was really stressed and the other group was doing quite well. Why were some of these families making it whie others appeared to be going under?

One factor that distinguished the highest stress group from the lowest was the characteristics of the children and their environments. Although older children tended to be more stressful than younger children, the child characteristics that separated the high stress from low stress groups of families were generally not fixed or immutable, but rather those that, within limits, could be changed. Parents in the high stress group had children with more difficult personality problems (often behavior management problems), fewer self-help skills and a greater degree of dependency, a lack of activities, and fewer services and prospects for independent living.

Another factor separating the highest from the lowest stress groups was the adequacy of the support that these people received from what we call the informal support network of spouse, parents, families, close friends, and other parents of handicapped children.

In problems of inadequate support from relatives, I thought at first that this reflected the loss of the extended family because of geographic mobility, i.e., families moving away from kin. On closer study, however, we found that in the highest stress group which rated relatives as much less helpful than relatives of the low stress group, eight out of ten families had relatives who were, in fact, available; they just weren't helpful.

Parents described some such relatives. First there is the "poor baby" group. The mother would say, "I can't bring Johnny over to my mother's - all she does is say 'Oh, poor baby. If he wants a cookie, give him a cookie.'" Basically, such relatives baby the child, never making any demands on him. They simply refuse to think that he is capable of anything.

The second group is worse. They are the relatives who imply "There's nothing wrong with your child - there's probably a great deal wrong with you." There was a mother-in-law who said, and this is a quote, "If I had that kid for two weeks, he could talk." I suggested, "Well, give him to her for two weeks - you've got a winner here no matter what: You get a two-week break and it will shut her up for years." Then there's the line: "There's never been any of that sort of thing on my side of the family." You've heard that one. The third group of most helpful relatives is made up of grandparents who pretend that the child is absolutely normal. They say, "You're just too worried about it - he's a beautiful child and I don't want to hear any more about it."

The last group of stress-producing relatives consists of those who, if you say, "Oh! I had a terrible day," say, "I told you to institutionalize that kid - I told you there's no sense beating your head against the wall."

The data show pretty clearly that the informal support network is very important and is significantly related to stress in the family, so what can we do about it? I think we had better begin to talk about network therapy. We need to get better at creating responsive environments for parents so that they have sources of reinforcement and support out there.

Let me give you an example. There was a mother who had a young son who threw things - he would throw everything - cups, balls, books, furniture. She told me that if he didn't stop throwing things their house would be destroyed.

I developed a super program that got the child to stop throwing - *except* on Wednesdays and Saturdays. Then his throwing would reach all-time highs. The program was clearly falling apart. I asked his mother, "What happens on Wednesdays and Saturdays." She answered, "Well, those are the days that his father is home." I brought the father in and told him that we were working on the throwing and the child seemed to be doing well except on the days that the father was home. I asked if he had any idea why. He answered, "You're damn right I do. You know what? It's the only normal boy thing that this boy can do." I was extinguishing the only behavior that this man valued in his son. Can you imagine the support his wife was getting? You can't just think about who's going to reinforce the child; you also have to ask who's going to reinforce and support the child's mother. You have to be thinking of the other people around - do they understand what it *is that you're* trying to help the parent do?

With a larger group of 150 parents of autistic and communication impaired children, we decided to find out where people were getting their support. The parents we asked, identified as most helpful to them as the parents of a special child, parent-training and special education programs, their spouses, their own children, parent groups, the mother's relatives, and summer camp. Not much help was reported from public social or health services or from churches, although in our other studies parents have consistently identified their personal religious beliefs as important in coping. This study was conducted in North Carolina and parents ranked the TEACCH program as being significantly more supportive than other parent training or education programs. These ratings of helpfulness were not correlated with a measure of social desirability which suggests that parents were not just telling us what we wanted to hear.

Respite care was listed as nonexistent for two-thirds of the families. Another problem was that although every child had some sort of educational program, 58%

had no recreational program. We are trying to incorporate into our state-wide programs provisions for a supportive environment for parents that would include respite care and recreational programs. It's so easy to think only in terms of the child, even if you've got what's called a parent program. The focus of intervention often tends to be on getting parents to help in changing the behavior of the child. This is very important but is only one aspect of a good parent program. Equally important, we have to give parents the kinds of services and support that will enable them to maintain their self-respect as persons and have time for themselves and their other family members. Sometimes what parents need from professionals is more "permission" not to feel guilty for not spending their whole life on their child, and more encouragement to do things independently of the child.

What we can provide professionally is network therapy, in which we reach out and strengthen the informal reinforcing network a parent is part of. We can help parents identify another network they can belong to, and that is NSAC. Parents can provide support for each other that cannot come from a professional. Professionals must acknowledge that they are but a moment in these children's lives. Only if a parent has an adequate continuing support network, can he or she hope to cope with the ongoing stress of caring for an autistic child.

PREPARED STATEMENT OF DISABILITY RIGHTS EDUCATION AND DEFENSE FUND

The Disability Rights Education and Defense Fund (DREDF)[1] is pleased to submit testimony in this historic hearing. We commend the Select Committee and its Chairman, Representative Miller, for the concern and interest for disabled children and their families which is demonstrated by this hearing. DREDF shares the commitment of this Committee to make families with disabled members visible and to make their needs a matter of top national priority. Too often the rhetoric of the 1980's about families and family values presumes that all members are white, middle class, and able-bodied. This Committee's effort to solicit the concerns and views of families of disabled children demonstrates a true commitment to all children and their families.

DREDF, an organization run by disabled adults, works closely with parents of disabled children. Initially our work involved individual and group advocacy to attain educational rights under the Education for All Handicapped Children Act (EHA). Our involvement in the educational rights of disabled children stems from our fundamental commitment to the full integration of all disabled people into the American mainstream. For this reason, our work in the area of education has focused on attaining integrated placements for children who have historically been educated in segregated facilities. The purpose of education is preparation for future adult roles. Segregated education is based on the view of disabled people as dependent. A child who is segregated from his/her peers is deprived of the critical preparation in social development necessary to interact as an adult in the mainstream of American life. Segregated education is tied historically and philosophically to institutionalization. Integrated education is the foundation of the goals of the disability rights movement of independence, autonomy, dignity, and productivity.

Our work on educational integration has been with families who have made the decision to keep their severely disabled children at home. This is the most fundamental "integration" for the child and for the family. These families claim the right to be part of their communities. They have rejected recommendations by doctors and social workers to institutionalize their children. They want to function as a family. Unfortunately, the service delivery system is designed to penalize them for their choice. Services which would be available for their children in out-of-home placements are unavailable at home. This is so despite the fact that providing services in the home is significantly less expensive.

Currently, California is serving about 64,000 people with severe disabilities via 21 regional centers, at a cost of approximately $206 million per year. About 8,000 persons are in eight state hospitals at a cost of $304 million per year.[1] The average service costs for each of the 1,300 children living in California's state hospitals is about $38,000 per year.[2] Those children living in group or family care homes cost about $2,500 per year.[3] Families receiving respite (in- and out-of-home) services cost about $237 per year.[4] Hence, the State of California spends about $59 million per year to support placement of children out of their homes. Only about $5 million is spent to assist families in keeping children at home with their families.[5]

The studies confirm that provision of respite services for families with severely disabled children is a major factor in preventing institutionalization.[6]

Nevertheless, California instituted massive respite care cuts in 1984. DREDF represented many parents in their appeals. Through this process we became intimately familiar with the daily lives of families with severely disabled children. Each family that we represented had an undying commitment and a willingness to endure unbelievable hardship to succeed in keeping their severely disabled child at home. Parents who make this decision should not be constantly tested—often to the point of family and personal dysfunction. These parents should be rewarded—not penalized.

---

[1] DREDF is a national disability civil rights organization dedicated to securing equal citizenship for 36 million disabled Americans. DREDF accomplishes its mission through education and advocacy. DREDF has headquarters in Berkeley, California and a governmental affairs office in Washington, DC.

[1] State Council on Developmental Disabilities, California Developmental Disabilities Plan—1984-86, part 1, p. 35 (Sept. 23, 1983).

[2] Id., part III, p. 36.

[3] Id.

[4] Id.

[5] Id.

[6] See, State Council on Developmental Disabilities, Respite Services for Californians with Special Developmental Needs: California Institute on Human Services, Sonoma State University (May 1982).

A brief description of one of our cases illustrates the problems with public policy in this area. In one case, a single mother with two sons had recently started a training program in dental technology after many years on welfare. She had someone to care for her disabled son between the time he came home from school and she came home from work. The state threatened to take away this service. The only option for this mother was to return to the welfare rolls or to place her well-adjusted, active child in an institution.

All of the cases involved children (often teenagers) who require constant care for all daily activities—eating, dressing, toileting, etc. Many children must be lifted ten to twenty times a day. The emotional and physical strain on parents (often mothers) is tremendous. This is exacerbated by the fact that every service—education, respite, equipment, recreation, transportation—requires a fight. Nothing comes to those who sit and wait for it. Not only are disabled children viewed as second-class citizens, but their parents are treated as such as well. Parents who fight for services are characterized as "pushy", "aggressive", or simply "crazy". The pressures are always present. The child brings joy—the fights bring anguish.

DREDF is pleased that this Committee took the opportunity to hear from parents themselves. They are not asking for pity—they are asking for support. Day care services—lacking as they are for all children—are unavailable for severely disabled children. Respite care services are essential to keep families together and children at home. These families deserve our respect. This hearing gives them your respect. We are hopeful that your exploration of these issues will form the foundation of a comprehensive support-services policy for disabled children and their families. Thank you for your interest and your action on this important issue.

UNITED CEREBRAL PALSY®
ASSOCIATIONS, INC.
66 East 34th Street, New York, N.Y. 10016
(212) 481-6300

April 30, 1985

Mr. George Miller
Chairman
Select Committee on Children,
Youth and Families
U.S. House of Representatives
385 House Office Building Annex 2
Washington, DC 20515

Dear Mr. Miller:

I appreciate your letter of April 15 which addressed the area of "Families with Disabled Children: Issues for the Eighties."

I'm glad our materials were helpful; and we will, indeed, forward to you our latest data on child abuse, disabilities, and respite care when finalized. At this point, questionnaires are still being received, and Dr. Shirley Cohen and I hesitate to release our information until we have completed our preliminary survey.

I have, however, enclosed for you our National UCPA, Inc. Policy Statement on Child Abuse as well as our Statements on Respite Care and Family Life Skills. Lastly, is a copy of our most recent UCPA News which includes an article on child abuse which details our current activities.

Please let Dr. Cohen and I know if we can be helpful to you in the future, and we will forward our report to you as soon as possible.

Sincerely,

Rachel Warren

Rachel Warren
Program Consultant
UCPA, Inc.

Shirley Cohen/rw

Shirley Cohen, Ph.D.
Hunter College

RDW/gh
Enclosures
cc: James Introne John Sieyp Mike Morris

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(212) 481-6300

Family Life Skills

WHEREAS UCPA, Inc. and its affiliates were established by families and

WHEREAS it is the goal of Family Life Skills to enhance all individuals' ability to control their own destiny through the teaching of skills necessary to deal effectively with the environment, and

WHEREAS Family Life Skills enhances the physical, social, and psychological growth and development of the individual as a progression towards interdependence or independent living, and

WHEREAS Family Life Skills encourages the evolution in life-style, appropriate to his/her developmental level, for the individual and his/her family

THEREFORE BE IT RESOLVED THAT UCPA, Inc. and its affiliates make a conscious effort to promote opportunities for families to develop these skills at all stages of life.

BE IT FURTHER RESOLVED THAT UCPA, Inc. and its affiliates provide access to community resources and identify and seek to alter public policies that discourage support to families.

Approved: Executive Committee - 9/25/82

LEONARD H. GOLDENSON, CHAIRMAN OF THE BOARD · JACK HAUSMAN, VICE CHAIRMAN · NINA EATON, VICE CHAIRMAN · HOWARD C. MILLER, JR., VICE CHAIRMAN · GEORGE S. DOLIM, PRESIDENT · WILLIAM BERENBERG, M.D., VICE PRESIDENT, MEDICAL AFFAIRS · EARL H. CUNERD, EXECUTIVE DIRECTOR

UNITED CEREBRAL PALSY®
ASSOCIATIONS, INC.
66 East 34th Street, New York, N.Y. 10016
(212) 481-6300

FAMILY LIFE SKILLS

Definition

There is an increasing awareness that it is a human right for all to control their own destiny to the extent that each is able. It is the goal of Family Life Skills to enhance all individuals' ability to control their own destiny through the teaching of skills necessary to deal effectively with the environment: family relationships, interpersonal relationships; stress & crisis coping skills; utilizing community resources; money management; selecting and adapting a dwelling place; time management; constructive use of leisure time; personal hygiene and grooming; clothing selection and adaptation; nutrition, meal planning and dining.

Goals/Philosophy

It is the overall goal of Family Life Skills to enhance the physical, social, and psychological growth and development of the individual as a progression towards interdependence or independent living.

Other goals are:

- To foster a positive self-image.
- To encourage the evolution in life-style, appropriate to his/her developmental level, for the individual and his/her family

Program Aspects

Family Life Skills represent a complement of many skills which will enhance the quality of life for the family unit. Planned Life Skills training can strengthen the life of individual family members as well as that of the person with a disability. The skills should be offered in the context of services for the total family, as a system of family supports. For example, a mother's time-management concerns may be alleviated when her son achieves goals of clothing care.

Family Life Skills are a crucial vehicle through which a person with a disability can be assisted to meet human requirements for a fulfilling life and sound mental health; directly in some areas (housing, money management, clothing, etc.) and indirectly in other areas (social interaction, self-worth, belongingness). Family Life Skills then are a preventive tool which supports good mental health through positive interpersonal relationships and management skills.

LEONARD H. GOLDENSON
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PRESIDENT
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VICE PRESIDENT
MEDICAL AFFAIRS
EARL H. CUNERO
EXECUTIVE DIRECTOR

Family Life Skills are psycho-social and developmental in nature. Medical, therapeutic, and rehabilitation engineering linkages are necessitated when special adaptations of the environment are required.

Family Life Skills are dynamic and change throughout the life cycle. Opportunities furthering skill development should be available to promote interdependence within the family unit and within the community.

The following are examples of program implications of the life-cycle approach:

- Parents of an infant may require assistance in use of community resources, time management, money management.
- Adult consumers in a vocational program may benefit from tutoring in use of leisure time, money management, or volunteer development.
- Staff of a Living Arrangements program may elect consultation in interpersonal relationships or budgeting.
- Older parents whose son or daughter has moved out to his/her own apartment may need assistance in restructuring their own time.

No one organization, school, or agency should assume total responsibility for Family Life Skills. Instead, a shared responsibility is indicated. Programs within UCP affiliates should support ties to the family and encourage use of other community resources. Wherever possible, the community should be the teaching/learning laboratory. Cooperative programs might occur with other agencies providing services to the developmentally disabled, County 4-H and Extension Programs, Public Schools, Infant Development Programs, Adult Education Programs, Visiting Nurses and Homemaker/Home Health Aide Agencies, Planned Parenthood, Vocational Rehabilitation, Consumer Credit Counseling, etc.

Methods of teaching may be through informal tutoring or in planned classroom activities. Family Life Skills must be planned for and integrated into all aspects of the program continuum.

Public Policy

This will include involvement in:

- Increased access to community resources.
- A policy which supports the concept that funding follows the individual.

UCP should identify and seek to change/alter public policies that discourage support to families.

Approved: Executive Committee - 9/25/82

UNITED CEREBRAL PALSY®
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66 East 34th Street, New York, N.Y. 10016
(212) 481-6300

CHILD ABUSE AND NEGLECT

WHEREAS UCPA, Inc. has clearly recognized the rights of people with disabilities by developing and adopting the Bill of Rights for the Disabled and

WHEREAS UCPA, Inc. promotes research that may lead to the elimination of causes of cerebral palsy by the year two thousand, and

WHEREAS significant progress has been made in decreasing the incidence of cerebral palsy, and

WHEREAS each year many children below the age of 5 years acquire cerebral palsy largely as the result of traumatic head injuries due to confirmed cases of child abuse, and

WHEREAS research has clearly shown that children born with disabilities are at a higher risk for child abuse, and

WHEREAS the Surgeon General of the United States has recently indicated that the abuse of children and other forms of family violence now represent a major health crisis in this country,

NOW THEREFORE BE IT RESOLVED that UCPA, Inc. promote research regarding the incidence, intervention and prevention of child abuse and neglect.

BE IT FURTHER RESOLVED that UCPA, Inc. utilize some of its resources to collect, review and disseminate material on the incidence, prevalence, identification, and strategies of intervention in child abuse and neglect for UCP affiliates.

BE IT FURTHER RESOLVED that UCPA, Inc. encourage other organizations such as the American Academy for Cerebral Palsy and Developmental Medicine to develop a similar policy regarding child abuse and neglect and explore means whereby organizations can work together to address this major health problem.

Adopted: Members of the Corporation - 5/5/84

LEONARD H. GOLDENSON, CHAIRMAN OF THE BOARD
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ANNA EATON, VICE CHAIRMAN
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WILLIAM BERENBERG, M.D., VICE PRESIDENT MEDICAL AFFAIRS
JAMES E. [illegible], EXECUTIVE DIRECTOR

UNITED CEREBRAL PALSY®
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(212) 481-6300

Respite Care

WHEREAS Respite care is a service providing temporary relief for the primary caregiver which is necessary to maintain or strengthen the bonds of the family unit and

WHEREAS This support to families can also reduce or prevent unnecessary disruption of family life and possible institutionalization and

WHEREAS Respite Care promotes positive changes of life style for the family and consumer since it frequently fosters movement towards a living arrangement in the least restrictive environment

THERFORE BE IT RESOLVED that affiliates should ensure the availability of a variety of models of respite care for families.

BE IT FURTHER RESOLVED that UCPA and its affiliates advocate for adequate funding for Respite Care from government and private sources

---

Approved: Executive Committee - 9/25/82

LEONARD H. GOLDENSON CHAIRMAN OF THE BOARD
JACK HAUSMAN VICE CHAIRMAN
NINA EATON VICE CHAIRMAN
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(212) 481-6300

RESPITE CARE

Definition

Respite Care is a service which provides temporary relief for the primary caregiver.

Goals/Philosophy

Respite Care is a service for families which is necessary to maintain or strengthen the bonds of the family unit. This support to families can also reduce or prevent unnecessary disruption of family life and possible institutionalization. Respite Care promotes changes of life style for the family and consumer since it frequently fosters movement towards a living arrangement in the least restrictive environment.

Program Aspects

Every affiliate should ensure the availability of respite care for families, since it is a priority of the national organization. Consumers should be intimately involved in planning and implementing the service and should be given the opportunity to choose from a variety of flexible models. Such a continuum can be assured through close collaboration with other generic community agencies.

Close association with the family will lead to identification of needs within the family unit. Therefore, a Respite Care service must relate to a case management system that can access other supportive services.

While the recipient of Respite Care is the primary caregiver, the service also offers enriching experiences for the consumer.

Public Policy

For the first time, Respite Care has been promoted by the federal government through the Title XIX, (Medicaid) Home and Community Based Services Waiver. Since such a service is a state option, affiliates should work for its inclusion in the service continuum and then assist states in operating this program.

LEONARD H. GOLDENSON
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MEDICAL AFFAIRS
EARL H. CUNERD
EXECUTIVE DIRECTOR

All levels of UCP should advocate adequate funding for Respite Care, particularly from non-medical sources such as the Title XX, Social Services Program.

Approved: Executive Committee - 9/25/82

THE FAMILY

A Problem Professionals Can't Ignore

The Surgeon General has publicly stated that "... family violence remains mankind's 'dirty little secret'." Its victims are its most vulnerable members—the quite young and quite old. Homicide is the fifth major cause of death among children, ages one to eighteen. Within that figure are the number of infants *under a week* old, 4,500 per year. Two thirds of the killers are parents. In addition about 13,000 children ranging in age from one week to one year are killed each year. Three of every four killers are parents of the murdered child. The National Center for Child Abuse believes that a *minimum* of two million children suffer physical and mental abuse each year. The Center is receiving 800,000 reports of child abuse each year, and the majority of abusers are parents.

Family violence tends to escalate during periods of economic stress. Present figures are probably low, and a truer statistical picture would make the present problem larger. Thirty nine states have reported an increase in the incidences of child abuse, according to the Children Protective Services.

To the willful infliction of pain of injury must be added the withholding of food, medicine, and clothing—the use of restraints for discipline, unreasonable confinement, and sexual abuse, the last of which may be inflicted (incredibly) even on infants.

Neglected and battered children, often victims of malnutrition and infections, as well as physical violence, may suffer permanent physical and mental impairment. These children are also particularly prone to neurological damage.

The United Cerebral Palsy Governmental Activities Office reported in 1977 that of the 12,000 new cases of cerebral palsy occurring each year approximately 1,500 were the direct result of child abuse. By 1982 the total number of cases was reduced to 10,000 a year. Of these 2,000 are acquired impairment. The causes of the acquired cerebral palsy are predominantly proven child abuse, falls and automobile accidents. It is, of course, a moot point how many of the "accidents" were the result of child neglect or unproven child abuse.

Lynne Messing

Specific Causes of Maiming

Children can be physically as well as psychologically maimed through sexual abuse. Sexual abuse of children is often discovered because the child has contracted veneral disease resulting in sickliness, hospitalization and permanent damage. Pregnancy and high risk progeny are the frequent end of sexual abuse.

Incestuous relationships result in pregnancies with high incidence of risk to the health of very young mothers. The babies are at high risk, due to the immaturity of the mother and high probability of hereditary birth defects.

Burn injury is a major cause of death and disability in childhood. The burning of children is deliberate abuse and often the consequence of a disturbed home situation. Children who have physical handicaps already, or any other feature that marks the child as different from other children (even precocity) are more prone to abuse. Mentally handicapped children appear to be more vulnerable for abuse or maltreatment than normal children. Children with certain temperaments are of high risk for abuse. Thus the child with birth defects or differences is apt to be in double jeopardy.

The emotional trauma of the victimization, verbal, physical or sexual is enormous. Most abusers were abused as children. Disease is transmitted from generation to generation by emotionally stunted parents. And these abused people were more intact ones who made it to adulthood; intact enough to form physical relationships and procreate.

Responsibility of Human Service Providers

The social, psychological, and academic problems associated with child maltreatment make this problem a crucial one for health providers as well as educators. Ignoring the problem will *not* make it go away. Yet an examination of many texts in special education reveals almost no address to this issue. This lack in educational materials is surely a cause and effect of the failure of teacher training programs to cover the subject.

Ignoring the problem is irresponsible for health providers and special educators. It is particularly irresponsible because professionals can make a difference in alleviating this national problem.

This is excerpted from an article submitted to "ACTA Paedologica" by June B. Mullins, Ph.D., Special Education Department, University of Pittsburgh

UCPA PROFESSIONAL SERVICES ACTIVITIES

In 1984, a Policy Statement regarding Child Abuse was approved by the Corporation of UCPA, Inc. Initial program activity included a review of the literature with summaries of identified programs cited in *Respite Care: Principles, Programs and Policies* by Cohen and Warren: (Austin: Pro-Ed Publishers, 1985).

John Siepp, Director of Professional Services Program Department; Rachel Warren, Program Consultant; and Dr. Shirley Cohen, Professor, City University of New York will be presenters in a panel on child abuse at the Annual Meeting of the Council for Exceptional Children in April, 1985.

Cohen and Warren are presently conducting a Preliminary Survey on Child Abuse. Some 71 affiliates with pre-school and respite care programs were mailed questionnaires in February. Results will be available to all affiliates. Direct any communication to Rachel Warren, PSPD.

HUNTINGTON BEACH, CA, *April 15, 1985.*

GEORGE MILLER,
Chair, House Select Committee on Children, Youth and Families, Room 385, House Annex No. 2, Washington, DC.

Thank you for contacting me concerning the hearing scheduled on April 19, 1985 in Anaheim. As I am unable to attend, I submit this letter.

I combine personal experience with a great deal of interface with families over the past thirteen years and also as a professional having acted as director of Developmental Disabilities Area Board XI during the past 6½ years.

First, let me state that becoming a parent of an infant having developmental special needs is an unexpected dilemma for which no one can be prepared. If you survive the grieving process, can now and again combat the systems and the emotional upheaval, you may one day be fortunate enough to learn to accept and love the person who will always be dependent on you. You'll spend a lifetime defending the disabled family member's worth/value against spouse, family members, professionals who practice their trade, a generally cruel and insensitive general public and public policy that is shortsighted and hypocratically inconsistent.

Attempts to provide early intervention to infants are encouraging and critical as are efforts to provide an opportunity whereby infants/children can be maintained at home. The major flaw, I fear, is that the majority of proposals place all families having disabled members into a "welfare mentality" criteria. One day perhaps it will be recognized that no correlation exists between having a disabled child and welfare/low income.

I recall that when, for no apparent reason, my own daughter's rapid regression at ten months old, caused us endless frustration in attempting to find answers and help. Instead, it was encouraged that permanent out of home residential placement be found. During the past thirteen years placement is always the response to requests for supportive resources. Incidentally, the placement suggested averages $1,500 per month and the place is one where two severely handicapped children were kidnapped and raped on two separate occasions.

Access to special education is the single most important available resource, at this time, to families. Often it is not appropriate nor is it ever free if one calculates the tremendous amount of time parents must volunteer in order to advocate minimally acceptable special education services.

We estimate the divorce rate among families having a disabled child at 80%. If dad hasn't permanently retreated to the den, he has decided to abandon this troublesome kid and fanatic spouse to find fun elsewhere. Like most, he pays no child support.

Mom, if she's skilled, may find work but can't find child care. Or if she can find someone to come in, they charge twice as much because the child is disabled. Remember, a disabled child, adolescent, or adult at no point in time often becomes able to enjoy any degree of independence with unsupervised peers. Someone must be responsible 24 hours each day, seven days a week—forever.

Attached is an example of a single mother who does not work and has attempted to take care of her seventeen year old son. Professionally, I receive at least two calls per week from single parents who cannot find day care, respite, recreation, medical or any degree of financial assistance support in order that they may survive the demands of taking care of their children at home. Instead, out of home residential placement is offered. This is shortsighted, at best.

Both development of resources and supplemental funding for supportive services to families having disabled family members must be made available within the existing systems.

Please advise if I may provide additional information.

Sincerely,

RHYS BURCHILL.

Enclosure.

Re: Herbie Langefeld

Langefeld provided verbal permission to share this letter & attachments. R.B.

[illegible] 15 1985

April 12, 85
25141 Sea Vista
Dana Point Ca
92629

Dear Rhys:

You told me to let you know how things were going well read this letter please + you'll see.

No one supports! us its always a damn fight.

Would you please read the enclosed letters and also forward the set to that Mrs. Churchill. I do not have her address. please send it to me. I think as soon as Herb is stronger and I am over this surgery I will ask if you can represent me again.

Also — The IHSS worker says Herb does not fall under the "protective custody" For God sake, I can't leave him alone and he will be 17 next month!

No one would work for 3^{50} per hour either.

I do have a question when you have time.

Thanks
Barbie
Langefeld

493-1243

P.S. Ms. Churchill never talked to my worker that time I called her, she spoke w. her supervisor and then I think Mrs. Thompson was "down on me" for going above her. Herb + I should be treated with respect and I am getting so sick of these agencies. I wish I could go on "60 minutes"!

25141 Sea Vista
Dana Point,Ca 92629
April 10,85

Mrs. Teddy Thompson, Social Worker
IHSS Social Services
Costa Mesa California

Dear Mrz. Thompson:

I thought I would beable to call you from Santa Ana Yesterday (no charge) because I had to have gum surgery up there. But I was in too much pain and dizzy to talk and they told Heidi to take me home to rest. I had my face swell up like a baloon back in February but could not take care of it. I went for 3 opinions to make sure I had to go thru this surgery again. Oh me !

Your letter was most upsetting. If you put Herb on arrearages I will louse the house, and then where will Herbie go?? McClaren Hall?

I am sending ½ of check but want you to realize our situation in case I could wait until June & July to give the checks.

For the 2 months Herb was in Shriners, I had no income and was going up to the hospital 10 hours a day every other day. Anyonewho has a child going thru this spinal fusion and another surgery would understand. The gasoline and food for Heidi and I was costing about $25. minimum. So Iam behind in my bills

In fact I owe the gas company $380. for 4 months when Herb was in cast here in L.R. we had to keep the house warm. I was going to ask if you knew any agencies that would still have gas funds. I could have gotten help when the bill was only 2 months due instead of 4 but th gas compray only NOW sent my overdue notice.

Then I had to pay Dr. Pan yesterday $300 ½ this mo and ½ nextn

In January I had to give up alimony as I could not afford a lawyer to fight Harry again. I am still paying $50 a month from 2 yrs ago to Jane McQuaid. I als o have had to take out a 3 mo in ad va ce Major medical as I have not been covered under MEDIcal since that time I could not get up there. Plus NO doctors around here will take medical. I have had lots of extra expenses for my Herbie thru nthese terrible 8 months. 6 prescriptions and medical only covered 1.

I saved the taxpaers about $50,000. having Herb's surgeries done with Shriners and also thousands of dollars by taking care of him at home here when both Shriners dr's and the "Regional center" recommended skilled nursing home.

The most difficult time of all has been these past weeks since Herb got cast off as he could hardly move and screamed in pain if we touched him so I have been up with him about every hr. at night.

I am going to send a copy of this letter to Protection and Advocacy and Mrs. Churchill

Another thing I am concerned about, if I pay this $247 back by CHECK now will it show that we did NOT receive this for Heidi's financial aid. ???? I knew You will be happy to hear Heidi was on Dean's List and is now taking 24 units and will be in Dance Production next mo.

Drop me a note if you can wait on this check but I am enclosing $120. I will not beable to talk for a few days

Barbie Langefeld

Enclosed your letter and check

We are still having to bodily lift Herb as we have not a Lift yet + he is 17 yrs. old. Can not sit even (C.P.) C.C.S. says they can not find the kind I nee' to Lift him myself!

COUNTY OF ORANGE
SOCIAL SERVICES AGENCY
LARRY M. LEAMAN, DIRECTOR

PLEASE SEND REPLY TO OFFICE CHECKED

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☐ [illegible]

Mrs. Barbara Langefeld
25141 Sea Vista
Dana Point, CA 92629

April 2, 1985

Dear Mrs. Langefeld:

As of this date the September 1984 overpyament of $247.79 remains uncollected, refer to letter enclosed.

Please contact me before 4/15/85, in order that we might make a plan of repayment. If I do not hear from you by this date, it will necessitate our having to put Herbie on arrears payment, in order to collect the $247.70 amount via our IHSS computer.

Sincerely,

T. Thompson

Mrs. T. Thompson, Social Worker
834-5429

TT:sl

Enclosures

COUNTY OF ORANGE
SOCIAL SERVICES AGENCY
LARRY M. LEAMAN, DIRECTOR

EASE SEND REPLY TO OFFICE CHECKED

☐ [illegible] N. ANAHEIM BLVD
P.O. BOX [illegible]
ANAHEIM, CA [illegible]

☐ [illegible] WESTMINSTER AVE
P.O. BOX [illegible]
GARDEN GROVE, CA [illegible]

☐ [illegible] W. WALNUT
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

■ [illegible]
P.O. BOX [illegible]
COSTA MESA, CA [illegible]

☐ [illegible] STREET
SUITE [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] CITY DRIVE, SOUTH
ORANGE, CA [illegible]
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible]
SANTA ANA, CA [illegible]
[illegible]

☐ [illegible]
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] AVE.
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
[illegible]
SANTA ANA, CA [illegible]

☐ [illegible] BROADWAY
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] STREET
P.O. BOX [illegible]
[illegible], CA [illegible]

☐ [illegible] CITY DRIVE [illegible]
ORANGE, CA [illegible]
P.O. BOX [illegible]
SANTA ANA, CA [illegible]

☐ [illegible] BEACH BLVD.
SUITE [illegible]
[illegible], CA [illegible]

January 18, 1985

Mrs. Barbara Langefeld
25141 Sea Vista
Dana Point, CA 92629

Dear Mrs. Langefeld:

The IHSS hours authorized effective January '85 and continuing will be 254.4, as I have increased time authorized for skin rubs. The 254.4 hours authorized is after 8.7 hours of respite have been deducted from Herbie's total need for services. You will receive a supplemental check for 42.7 hours for January '85 (254.4 eligible to 211.7 received.)

You will also receive (3) additional checks from the months of 7/84 ($20.45), 8/84 ($21.17), 9/84 ($21.17), as the computer did not send the retroactive wage increase from $3.45 to $3.55.

At this time the September overpayment, of 69.8 hours, can not be collected as previously discuss. In order to reconcile the computer a check should be made out to DSS/IHSS Program, in the amount of $247.79, in the lower left hand corner under memo please indicate September '84 overpayment.

It continues to be your responsibility to notify this agency when the respite person assumes more responsibility for Herbie's personal care, and when Herbie's program of care changes.

Please call me regarding any questions.

Sincerely,

Theodora Thompson

Mrs. T. Thompson, Social Worker
834-5429

TT:s1

CASE WESTERN RESERVE UNIVERSITY,
Cleveland, OH, April 4, 1985.

Select Committee on Children, Youth and Family, Room 385, House Annex 2, Washington, DC.

Enclosed you will find a list of publications from my study and reprints (or preprints) of pertinent papers.

A copy of the abstract, scheduled for presentation on May 22, 1985 at the American Psychiatric Association Annual Meeting, is also enclosed. The abstract focuses narrowly on the finding that the chronic stress of mothering disabled children does not cause Major Depression. In the paper I will report in addition that mothers of disabled children had a significantly higher rate of non specific psychological distress compared to controls, 30% and 16% respectively. Non-specific psychological distress, although it does not correspond to any specific psychiatric disorder, affects the quality of life of individuals and their ability to respond effectively to life's problems.

I will report also that the adverse effect of chronic stress on families is reflected in an increased rate of divorce. During a five year period, 12.2% of 230 married mothers of disabled children became separated or divorced, compared to 5.5% of 290 mothers of children free of physical disability. The difference is statistically significant.

Sincerely,

NAOMI BRESLAU,
Ph.D., Associate Professor of Sociology.

Enclosures.

Women's Labor Force Activity and Responsibilities for Disabled Dependents: A Study of Families with Disabled Children

NAOMI BRESLAU
Case Western Reserve University School of Medicine

DAVID SALKEVER
The Johns Hopkins University

KATHLEEN S. STARUCH
Case Western Reserve University

Journal of Health and Social Behavior 1982, Vol. 23 (June):169–183

Previous research demonstrated that the presence of young children in the home has a negative impact on the market work of the mother. However, the effects of women's responsibilities for the care of disabled family members have rarely been examined. This paper reports the results of a study of the impact of child disability on maternal labor-force activity. Data were gathered from 369 families of children with cystic fibrosis, cerebral palsy, myelodysplasia or multiple physical handicaps and from 456 randomly selected families with children free of disabilities from the same geographic area. Among two-parent families, child disability interacts with race and family income: It exerts a greater negative impact on maternal labor-force participation of black and low-income families, as compared to white and high-income families. Labor market activity of single mothers does not appear to be significantly affected by child disability either alone or in interaction with income and race.

Women's activities in the labor market have been dominated by the events of motherhood. Historically, the presence of young children in the home has had a powerful negative impact on the employment of the mother. Researchers point out that the presence of a young child plays a key role in the monetary considerations that lead to a mother's decision not to work outside the home. This is so because the cost of acceptable substitute child care often outweighs the potential contribution to family income from the mother's paid work (Cain, 1966; Mincer, 1962; Sweet, 1973). Public attitudes regarding child development, women's roles, and the satisfaction to be gained by women from family as opposed to market activities have also exerted a negative influence on their employment (Smith-Lovin and Tickamyer, 1978; Waite and Stolzenberg, 1976).

Although the presence of a small child in the home continues to inhibit maternal employment, Waite (1976) found that its effect decreased substantially between 1940 and 1960.

This research was supported by grants from the Cleveland Foundation and the C. S. Mott Foundation.

Address communications to: Naomi Breslau, Ph.D., Department of Epidemiology and Community Health, Case Western Reserve University School of Medicine, Cleveland, OH 44106.

Indeed, recent labor statistics attest to major changes in the maternal labor force. Labor force participation rates for married women with children under 6 years of age rose sharply from 26.5% in 1970 to 41.6% in 1978. For married women with older children (6–17 years old), this rate increased from 45% to 57.2%, and the increase for women who were household heads during this period was from 53% to 58.9% (U.S. Department of Labor, 1979). Waite (1976: 74–75) speculates that the decline of the negative effect of young children on employment "is probably due to increased wage rates for women, which increased opportunity costs of the withdrawl of the wife from the labor force, and to more favorable attitudes toward working mothers."

While the responsibilities of caring for small children may have become a weaker deterrent to women's market work, the effect of other responsibilities may be increasing. Recent statistics from the U.S. National Health Survey indicate a dramatic increase in the prevalence of childhood disabilities. The reported percentage of children in the noninstitutionalized population having activity limitation due to chronic conditions increased from 2.7% in 1970 to 3.9% in 1978. The corresponding rise in the prevalence of limitation in major activity (schooling) was from 1.3% to 2.0% (U.S. National Center for Health Statistics, 1972, 1979). Improvements in medical therapies, which increased the survival rates and prolonged the lives of children born with severe physical impairments, have contributed to this trend. The recent shift from institutional care to care in the home is undoubtedly reflected in these statistics, as well.

The research reported here focuses on the effect of a disabled child in the home on the mother's activity in the labor force. Disabled children can be expected to increase inordinately the child-care demands on families. This results from the children's greater dependence on others for self-care and mobility, the time parents must spend in obtaining medical and related services and in-home therapy, and the limited availability of substitute child care for disabled children. Such increased child-care demands would tend to inhibit maternal employment because they constitute additional nonmarket work in the home, and because of powerful cultural norms that assign to women the principal responsibility for the care of sick family members (Carpenter, 1980; Lewis and Lewis, 1977). At the same time, however, there are other consequences of child disability that may have an opposite effect. Added demands for purchased professional services increase the family's financial needs and could induce mothers to enter the labor force or remain in it. A similar effect may result from the psychological strain of caring for a disabled child and the associated increase in the psychic benefits for the mother of work outside the home.

Recently, Salkever (1982a, b) has examined this question using data from national household surveys for 1972 and 1975. The results indicate that children's disabilities do in fact reduce labor force activity of mothers. These studies also indicate that the effects are significantly greater for lower income, white families; for non-whites, the effects are not statistically significant. Although this research suggests a potential income differential in the impact of child disability on maternal employment, it has not fully explicated the basis for this observation. Furthermore, the effect of the severity of child disability on maternal labor force activity was not analyzed, nor did the sample include an adequate number of non-white families with severely disabled children to test and estimate effects on non-whites.

Our primary focus is on the following questions: Does child disability have a greater negative effect on maternal labor force activity in low-income families and black families than on high-income and white families? Does it, thereby, constitute a greater burden on the earning potential of low-income and black families, as compared to these other families? Economic forces, cultural factors, and patterns of family organization shape a different labor market behavior among black in comparison to white women, as previous research has consistently demonstrated (Cain, 1966; Landry and Jendrek, 1978; Sweet, 1973).

Hypotheses

Our central hypothesis is that childhood disability exerts a more negative effect on maternal employment of black and lower income families than of white and higher income families. Such racial and income differences can be expected to result from class-linked variations in the employment opportunities for women. Both income and race were used as variables in this analysis on the basis that each may index a different aspect of these class-linked variations.

Black and low-income mothers are more likely to hold blue-collar, low-skilled jobs, and therefore to be more affected by the presence of a disabled child in the home for the following reasons. First, conflicts between child-care demands and demands of the workplace may be greater for them because the types of jobs they have access to do not accomodate easily to flexible or part-time schedules or frequent absences (Cook, 1978). Second, the monetary benefits of hourly wage, low-paid work (part-time or full-time), net of the high costs of non-family care for disabled children, may be too insubstantial to constitute an effective incentive for market work. Third, as the primary motivation for maternal employment in low-income and black families is more likely to be financial need (Landry and Jendrek, 1978), their decision to work for pay would more likely be governed by these monetary considerations. In contrast, mothers in higher income and white families would have greater access to work in an office situation, which adapts more readily than many other employment situations to part-time work and is more tolerant toward absences. Furthermore, higher paying jobs are more likely to yield a surplus of earnings over the extra costs of child care. Finally, and perhaps most important, higher status jobs may provide psychological rewards even when they do not increase the family's net income. A pleasant or interesting part-time job may be a welcome activity, providing stimulation and relief from the routine chores of homemaking and the demands of caring for a disabled child.

A second consideration is the impact of child disability on the employed mother's hours of work. With respect to work hours, different consequences can be expected. Black and low-income mothers of disabled children are unlikely to respond to the conflicting demands of work and home by reducing their work week; they are more likely to respond by dropping out of the work force altogether. Therefore, we would not expect to find a substantial difference between the average hours worked by these women and those worked by comparable mothers without disabled children. White and high-income mothers, in contrast, are more likely to respond to the extra burden of a disabled child by taking a part-time rather than full-time job. These combined trends would result in greater reductions in hours of work for white and high-income, as compared to black and low-income, employed mothers, an opposite interaction effect to that expected for labor force participation. The net negative impact on the number of hours worked by white and high-income women would be attenuated, however, by the fact that—in the general population of working women—whites and women with high incomes have higher rates of part-time employment, as compared to blacks and those with low incomes (Landry and Jendrek, 1978). On balance, we would expect an average, weak, negative effect on hours of work of employed mothers.

Sample and Data

Families of children with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps were selected from among families attending four pediatric specialty clinics in two teaching hospitals in Cleveland, Ohio. Most children with these severe conditions are referred to tertiary medical institutions. Since the participating hospitals are two of the three tertiary hospitals in the Cleveland area, their clinical populations provide relatively representative samples of children in these diagnostic categories residing in the area. All Cleveland area families of patients in these diagnostic categories who were 3 to 18 years of age were asked to participate in the study. From 460 eligible families, 369 (80%) complete and usable interviews were obtained.

For a comparison group, a three-stage probability sample was designed to represent all Cleveland area families with one or more children 3 to 18 years old. From 530 eligible families, 456 (86%) complete interviews were obtained. In each family, a randomly selected child between 3 and 18 was defined as the Index Child, and was the focus of an extensive inquiry, comparable to that concerning the disabled child. Data were gathered from mothers in which $\overline{Y}$ = labor force participation; c_1 to c_6 = six predictors of labor force participation used here as covariates (AGE, AGE², EDUCATION, CHILDREN, YOUNGEST, HEALTH); x_1 = RACE; x_2 = O-INCOME; d_1 = DISABLED (see Table 1). The interaction hypotheses would predict that: (1) B_{10} and B_{11} are statistically significant, and (2) the size and sign of the coefficients in the equation indicate a greater negative effect for black and for low-income families. In a second set of analyses, weekly hours worked by employed mothers was the dependent variable, using the same set of independent variables but without interaction terms.[5]

Analysis of subjective data collected from mothers, regarding the impact of child disability are presented to corroborate the regression results. An eight-item scale was used to measure role restrictions attributed by mothers to having a disabled child in the home.[6] The items describe a mother's curtailed possibilities for employment, going back to school, following her own interests, and day-to-day activi-

TABLE 1. Means and Standard Deviations (in parentheses) of Variables Included in the Model by Marital Status and Child Disability

	Two-Parent Families		Single-Parent Families	
	With a Disabled Child (n = 278)	Without a Disabled Child (n = 361)	With a Disabled Child (n = 91)	Without a Disabled Child (n = 95)
LFP*	.43 (.5)	.48 (.5)	.47 (.5)	.58 (.5)
HOURS*†	27.1 (13.1)	30.5 (14.1)	35.4 (12.8)	38.8 (10.2)
AGE*	36.7 (8.0)	38.3 (8.7)	37.2 (9.3)	35.7 (9.3)
AGE²*	1413.6 (633.2)	1546.6 (698.9)	1467.2 (800.2)	1361.8 (719.4)
EDUCATION*	12.1 (2.3)	12.8 (2.1)	11.3 (2.5)	11.9 (2.1)
CHILDREN*	2.7 (1.4)	2.3 (1.2)	2.5 (1.6)	2.2 (1.3)
YOUNGEST*	7.2 (4.8)	8.4 (5.2)	9.1 (4.8)	8.1 (5.2)
HEALTH*	1.9 (.7)	1.8 (.6)	2.3 (.8)	2.0 (.7)
RACE*	.12 (.3)	.20 (.4)	.53 (.5)	.67 (.5)
O-INCOME*	19.5 (10.1)	22.5 (14.9)	4.7 (4.8)	4.2 (4.0)
ADL*	5.6 (6.2)	0.8 (2.0)	4.2 (5.4)	0.5 (1.6)

* LFP—labor force participation: the first dependent variable, a dummy variable scored 1 if the mother was employed at the time of the survey, 0 if she was not; the predicted value of this dichotomous variable in this model may be interpreted as the probability that a mother was employed, given the values of the independent variables.[3]

HOURS—number of hours per week an employed mother worked: the second dependent variable.
AGE—the mother's age in years.
AGE²—the mother's age in years squared.
EDUCATION—the number of years of schooling the mother completed.
CHILDREN—the number of children under 18 living at home.
YOUNGEST—the age of youngest child.
HEALTH—mother's subjective health assessment, rated as 1 = excellent, 2 = good, 3 = fair, 4 = poor.[4]
RACE—a dummy variable scored 1 = black, 0 = other.
O-INCOME—other income: the total annual family income from sources other than mother's earnings for the past year (in thousands of dollars).
DISABLED—a dummy variable scored 1 = a disabled child is present, 0 = no disabled child present.
ADL—activities of daily living: the level of disability of the Index Child.

† For employed mothers only.

in home interviews using a structured questionnaire including self-administered instruments.[1]

Model and Method of Analysis

The effect of child disability on maternal employment is examined in this study within the framework of prior research on labor market activity of married women (Bowen and Finegan, 1969; Cain, 1966; Heckman, 1974; Landy and Jendrek, 1978; Sweet, 1973; Waite, 1976, 1980); most research on maternal employment has focused exclusively on married women. The factors most frequently identified as having an influence on wives' employment can be classified in four categories: (1) domestic demands, including number and age of children, (2) mother's earning potential, including her age and education, (3) socioeconomic factors, including husband's income and race, and (4) labor market conditions, including area unemployment rates for women. Of these, only labor market conditions are not included in this study because they are constant across the sample. Mothers' health, a variable rarely included in previous research, is added to this analysis, as there is some evidence that mothers of disabled children may be in poorer health than other mothers,[2] a fact that may account for differences in employment rates. Since the focus of this analysis is on the differential impact of childhood disability on the labor supply of mothers by race and income levels, other variables that influence mothers' employment are included in the model as covariates, in order to control for their effects. Data are analyzed separately for married and for single mothers.

Means and standard deviations of the variables in this study, cited by marital status for families with and without disabled children, are presented in Table 1. The activities of daily living (ADL), the level of disability of each index child, were determined from a six-item Likert scale, which measures the extent to which the child gets help in each of the following activities: eating, dressing, washing, toileting, going up or down stairs, and going outdoors. Responses on each of the items range from "never" (0) to "most of the time" (3); and scale scores, computed by summing over the six items, range from 0 (no disability) to 18 (high disability). Internal consistency reliability (Cronbach's alpha) is .88.

Information on income from sources other than mother's earnings (O–INCOME) of families with employed mothers was obtained directly only for the randomly selected families (i.e., those without a disabled child). For families of disabled children with working mothers, values on O–INCOME were estimated as a function of other variables: marital status, average earnings of husband's occupation (using detailed three-digit occupational codes), husband's employment data, education, age, race, rent, number of children, and alimony. A regression of reported family income exclusive of mother's earnings (O–INCOME) in the random sample of families was used to calculate weights for these predictors. This regression predicted 50% of the variance in the dependent variable. We examined also the possibility that race and marital status interact with other predictors of O–INCOME. Such interactions would indicate the desirability of estimating weights in separate equations by race and marital status groups. A hierarchical model with such interactions was tested. The increment to explained variance in O–INCOME attributable to the set of interactions was not statistically significant (F = .802; df = 11,150). We concluded that weights estimated on the total random sample could not be improved upon by calculating them separately on black and white, married and unmarried sub-groups.

Missing data present little problem in this analysis, since information on any of the independent variables was missing in only a few cases (no more than 0.5%). When values were missing, the mean of that variable for the cases in which values were available was substituted (Cohen and Cohen, 1975).

To examine and estimate the effects of child disability on maternal labor force participation as conditioned by family income and race, an ordinary least-squares linear model was used. Differential effects of child disability were tested as interactions between child disability and moderator variables of interest (namely, family income and race) in the following hierarchical model:

$$\bar{Y} = B_1c_1 + \ldots B_6c_6 + B_7x_1 + B_8x_2 + B_9d_1 + B_{10}d_1x_1 + B_{11}d_1x_2 + a.$$

ties. Responses range from "strongly disagree" (1) to "strongly agree" (5); and scale scores range from 8 (none) to 40 (many restrictions). Internal consistency reliability of the scale (Cronbach's alpha) is .86.

RESULTS

The Presence of a Disabled Child in the Home

Table 2 shows the regressions of maternal labor force participation for two-parent and single-parent families; ordinary least squares unstandardized partial regression coefficients are presented. As can be seen in this table, the results for two-parent families confirm our expectations. Coefficients for the two interaction terms, DISABLED × O-INCOME and DISABLED × RACE, are statistically significant, indicating that the labor force participation regression slopes on DISABLED change with the values of O-INCOME and RACE. Further, from the coefficents in the equation we can conclude that child disabilty has a stronger negative effect on low-income and black families than on high-income and white families. The results leading to these conclusions are presented in detail in the paragraphs below.

TABLE 2. **Hierarchical Regressions of Maternal Labor Force Participation by Marital Status (partial unstandardized regression coefficients; standard errors in parenthesis)**

Independent Variable	Two-Parent Families (n = 639)	Single-Parent Families (n = 186)
AGE	.0479*	.0239
	(.0191)	(.0244)
AGE²	−.0007*	−.0004
	(.0002)	(.0003)
EDUCATION	.0350*	.0423*
	(.0093)	(.0162)
CHILDREN	−.0059	−.0091
	(.0171)	(.0271)
YOUNGEST	.0231*	.0296*
	(.0056)	(.0092)
HEALTH	−.0226	−.1762*
	(.0294)	(.0478)
RACE	.1323*	−.2354*
	(.0657)	(.1054)
O-INCOME	−.0085*	−.0156
	(.0018)	(.0121)
DISABLED	−.1302	−.1570
	(.0838)	(.1343)
DISABLED × O-INCOME	.0068*	−.0016
	(.0034)	(.0152)
DISABLED × RACE	−.2282*	.1597
	(.1111)	(.1367)
Constant	−.732	.090
R²	.105	.317

* Coefficient exceeds twice its standard error ($p < .05$).

The regression slope of labor force participation on O-INCOME in the randomly selected families, measured by the coefficient of O-INCOME (from which is partialled DISABLED × O-INCOME), indicates that a drop of $1,000 in O-INCOME increases by almost 1% the likelihood that a mother is employed. This estimate replicates closely the estimated effect of husband's income on the employment of married mothers reported recently by Waite (1980) for a more homogeneous and younger cohort. For a family with a disabled child, the corresponding rise in labor force participation with a unit decrease in O-INCOME is by less than 0.2%.

From these results, the point of intersection of the regressions of labor force participation on O-INCOME for families with and without a disabled child can be calculated, and it can be determined whether the interaction is ordinal or disordinal; i.e., whether the rank order of the two samples with respect to labor force participation is constant or whether it is reversed with changes in O-INCOME (Kerlinger and Pedhazur, 1973:255). Family income exclusive of mother's earnings (O-INCOME) at the point of intersection of the two regression slopes is approximately $19,000, a value well within the range of interest in this study. It is also the median O-INCOME of two-parent families with disabled children. The interaction is thus disordinal: at low levels of O-INCOME (<$19,000) a mother of a disabled child is less likely to be employed than is a mother of children free of disabilities, whereas when O-INCOME is high (>$19,000) the probability that the mother of a disabled child is employed is greater.

To describe the nature of the interaction more clearly, changes in labor force participation rates that are associated with having a disabled child were estimated at several representative income levels (Table 3). An estimated

TABLE 3. **Estimated Effects on Employment Probabilities of Married Mothers of Disabled Children by Family Income Exclusive of Mother's Earnings**

O-INCOME	Estimated Effects	% of Sample (cumulative)
5,000	−10%	3
7,000	−8%	8
10,000	−6%	15
15,000	−3%	33.3
19,000	0%	50
20,000	0.5%	65.5
23,000	3%	80
25,000	4%	86
30,000	7%	92

effect of a disabled child, given a certain level of O-INCOME, is the difference between the predicted probabilities of employment of a mother with a disabled child and one without such a child at that level of O-INCOME, using the coefficients produced in the regression. For example, in comparison with a mother of children free of disabilities but with the same O-INCOME, the probability of a mother of a disabled child with O-INCOME of $5,000 being employed is, on the average, 10% lower. When O-INCOME is $10,000, the negative effect of a disabled child is smaller; specifically, the probability of maternal employment is reduced by 6%. The presence of a disabled child in families whose O-INCOME is greater than $19,000 has a postive impact on maternal employment. For example, when O-INCOME is $25,000, the probability that a mother of a disabled child is employed is 4% higher than when a disabled child is not present. An inspection of Table 3 reveals also that compared to only one-fifth of the families with incomes associated with increases of 3% or more, one-third of the families are at income levels associated with reductions of 3% or more in employment probabilities. On the whole, however, the opposing effects cancel each other out. It is not surprising, therefore, that the main effect of child disability on maternal labor force participation (as estimated in an equation that does not include interaction terms) is weak and statistically Insignficiant (B = −.0228; S.E. = .0397).

As O-INCOME values for working mothers of disabled children were estimated as a function of other variables, it could be argued that the markedly attenuated regression of labor force participation on O-INCOME in two-parent families with disabled children might, in part, be an artifact of a greater measurement error of O-INCOME in this group. It might also be argued that, in using weights calculated on the random sample, we have overestimated the actual O-INCOME for employed mothers of disabled children—an error that would indeed result in a downward bias of the coefficient of maternal employment on O-INCOME in this sample. Indeed, in applying weights estimated on the random sample to families with disabled children, we make the assumption that the same set of factors predict O-INCOME in the same manner in both populations. That is, we assume that (1) there are no unique sources of O-INCOME in the disabled sample, and (2) the principal predictors have similar weights in both groups. With respect to the first assumption, it should be noted that the major assistance program to families of disabled children (i.e., Crippled Children Services) supports the provision of medical services, but does not transfer cash payments to families. As to the potential differences in the weights of predictors used to generate O-INCOME, it could be asked if husband's income, the single most important predictor of O-INCOME in two-parent families, might be significantly reduced by the presence of a disabled child in the home. However, previous research by Salkever (1982b) showed that paternal earnings are not significantly decreased by the presence of a disabled child. It seems doubtful, therefore, that our estimation procedure has systematically overstated O-INCOME for families with disabled children.

There is other evidence to suggest that our finding is not the result of statistical bias. First, the same sort of income interaction observed here was also reported by Salkever (1982a). Second, information on O-INCOME for non-working mothers was obtained in the sample of disabled children directly from respondents, just as it was in the random sample. A comparison of O-INCOME distributions for non-working mothers in the two samples clearly shows a markedly greater proportion of low O-INCOME among non-working mothers with disabled children than among those without disabled children. The respective proportions of mothers with O-INCOME less than

\$10,000 are 18% and 5%, of those with O-INCOME of \$10,000–\$19,000, 40.5% and 32.8%, and of those with O–INCOME of \$20,000 and over, 41% and 62% ($p < .0005$). Mean O–INCOME of non-employed married mothers with disabled children is \$19,052, and of those without disabled children, \$25,377 ($t = 4.074$ (343); $p < .0002$). It is highly unlikely that such a large difference in income distribution could be explained by other factors, such as class differences in prevalence rates of children's disabilities. In this regard, it should be noted that income data from the United States Census Bureau's Survey of Income and Education, presented by Salkever (1982b), show much smaller differences between all families with and without disabled children.

The negative effect of a disabled child on the probability that a married mother is employed is almost three times as strong among blacks as among whites, 36% and 13%, respectively (Table 2). The coefficient for whites is not statistically significant, whereas the coefficient that measures the difference between the effect of disability on blacks and on whites is statistically significant.

The finding that child disability has a stronger negative effect on the labor market behavior of black and low-income wives than on that of white and high-income wives is supported by the subjective reports we collected from mothers regarding the extent to which child disability restricts their nonfamilial roles. On the scale measuring role restrictions, black married mothers of disabled children scored higher, on the average, than their white counterparts, 18.03 and 15.90, respectively ($t = 1.945$ (276), $p = .05$). The difference between low income (< \$10,000) and high income (≥ \$10,000) is even greater, 18.86 and 15.78, respectively ($t = 2.926$ (276), $p = .003$). On the item most directly related to employment—"I cannot take a job outside the home because of the child's condition"—a higher proportion of black than white wives expressed agreement, 27% and 19%, respectively; and proportionately more low-income than high-income wives expressed agreement, 31% and 18.5%, respectively. In sum, respondents' perceptions of the extent to which the care of a disabled child confined them to a domestic role and preempted employment corroborate the regression results on the labor market behavior of married mothers. Both sets of data indicate that child disability is a stronger deterrent to maternal employment in black and low-income families than in white and high-income families.[7]

As Table 2 shows, results on other determinants of employment of married mothers are in accord with past research. Mother's age has a curvilinear effect on employment, as indicated by the signs and statistical significance of the two age variables (see Landry and Jendrek, 1978, and Sweet, 1973, for similar results). With respect to level of education, our results indicate that an additional year of formal education raises the probability that a married mother is employed by 3.5% (see Bowen and Finegan, 1969; Cain, 1966; and Sweet, 1973). Number of children has no effect on the employment of wives in our sample, which comprises families with at least one child present in the home. In contrast, age of youngest child has a positive effect on the employment probability of married mothers: The likelihood that a married mother is in the labor force increases by approximately 2% with each additional year of age of her youngest child (see Cain, 1966; Sweet, 1973; and Waite, 1980). The effect on employment of a mother's rating of her general health is not statistically significant.

Table 2 presents also the unstandardized regression coefficients of labor force participation of mothers in single-parent families. This category comprises widowed, divorced, separated, and never-married mothers. In contrast with the results for two-parent families, interaction terms between the presence of a disabled child in the home and income or race are not statistically significant. The absolute value of the coefficient for the product term DISABLED × RACE, however, is greater than its standard error. The sign of the coefficient is positive, in contrast to the negative sign of the corresponding coefficient for two-parent families. This could mean that, whereas for two-parent families the negative impact of child disability is greater for blacks than for whites, among single–parent families the effect is the reverse. The negative effect of child disability among single mothers was found only for whites, reducing the probability of their employment by approximately 16%, whereas the employment probability of comparable blacks was unaffected.

Aside from its possible interaction with race, child disability does not emerge as a factor in labor force participation of single mothers. The model, however, does account for a substantial part of the variance (i.e., 32%) and three factors are found to have substantively as well as statistically significant effects. Mother's education and age of youngest child have strong positive impact on labor force participation of single mothers, just as they have for married mothers. In contrast, mother's health has a positive and statistically significant effect on the employment probability of single mothers only. We speculate that their close financial dependence on market work would induce healthy single mothers to seek work, leaving among the non-working single mothers a disproportionate number of those who are in poorer health. Conversely, since married mothers have more discretion regarding whether or not to work for pay (as their lower labor force participation rates show), their health is less likely to be a factor; and its relationship with employment status is, therefore, likely to be weaker.

In a second set of hierarchical regressions, we examine the effect of child disability on hours of work for employed mothers. The hypothesis, as stated above, is not one of interaction but rather of an average, weak, negative effect. Table 4 presents the results for two-parent and single-parent families. The coefficients of child disability are not statistically significant for either two-parent or single-parent families. The results, however, are consistent with our expectation, in that the coefficients are negative and are larger than their respective standard errors: for two-parent families, B = −2.3317 (s.e. = 1.6536), and for single-parent families, B = −2.9439 (S.E. = 2.4883). Furthermore, the regression coefficient of child disability calculated on the combined sample of two-parent and single-parent families is almost twice as large as its standard error: B = −2.5795 (S.E. = 1.3718; $p < .10$).

TABLE 4. **Hierarchical Regressions of Hours of Work for Employed Mothers by Marital Status (partial unstandardized regression coefficients; standard error in parenthesis)**

Independent Variable	Two-Parent Families (n = 290)	One-Parent Families (n = 98)
AGE	−.1217	1.3059
	(.9906)	(1.1575)
AGE^2	−.0017	−.0180
	(.0123)	(.0143)
EDUCATION	.0694	−.3839
	(.3629)	(.5573)
CHILDREN	−.1069	−1.0780
	(.7759)	(.9991)
YOUNGEST	.6172*	.3568
	(.2365)	(.3652)
HEALTH	.7141	.5981
	(1.2636)	(1.9037)
RACE	5.5000*	5.1904*
	(2.1638)	(2.4966)
O–INCOME	−.2063*	.3722
	(.0832)	(.2359)
DISABLED	−2.3317	−2.9439
	(1.6535)	(2.4883)
CONSTANT	32.931	14.474
R^2	.100	.167

* Coefficient exceeds twice its standard error.

Three factors in the model affect hours of work of married mothers: age of youngest child, race and O–INCOME (Table 4). As her youngest child grows older, an employed married mother increases her hours of work approximately one-half hour each year. Employed black mothers work, on the average, more than 5 hours in excess of white working mothers. Husband's income has a negative effect on hours of employment of working wives; an increase of $5,000 is associated with a reduction of one hour of work. These effects may measure changes from part-time to full-time employment more than small increments in hours of work. Thus, the racial difference probably reflects the smaller proportion of part–time workers among black than among white working wives. Our own data indicate such a trend, as do data presented by Landry and Jendrek (1978).

Of these three determinants of hours of work in two-parent families, only race is statistically significant in predicting hours of work of single mothers. We tested also the interaction effects of child disability with O–INCOME and race on hours of work, but failed to find evidence for such interactions for either two-parent or single-parent families.

The Impact of Severity of Child Disability. Severity of child disability was hypothesized to interact with family income (O–INCOME) and race, reducing (as the severity increases) the labor force participation of mothers in low-income and black families more than it reduced that of mothers in high-income and white families. "Activities of daily living" (ADL) measures the extent to which the child gets help in self-care and mobility. We chose this scale as an appropriate index of severity of disability on the grounds that it probably measures the burden of care imposed on parents more closely than other disability measures. Table 5 presents the regression of maternal labor force participation and hours of work on ADL interactions with income and race. Although these results are from analyses in which the total set of six covariates are entered before ADL and its product terms with O–INCOME and RACE, the coefficients of these covariates do not appear in Table 5, as they already appear in Tables 2 and 4.

Results on the effects of ADL on labor force participation in two-parent families are generally consistent with our expectations (see Table 5). The interaction between ADL and O–INCOME is statistically significant and with the hypothesized sign. The negative (linear) impact of severity of disability on maternal employment decreases with increments in family's income net of mother's earnings. The negative slope measuring this impact is steepest for those with the lowest incomes, and is reduced by .0008 with an income increase of $1,000. In Table 6, we present regression estimates for selected levels of O–INCOME and changes in employment probabilities associated with three levels of ADL at each of these income levels, following the technique described in Cohen and Cohen (1975:310–314).

TABLE 6. Estimated Regressions of Maternal LFP on ADL and Estimated Losses in LFP by ADL at Representative Levels of O–INCOME for Two-Parent Families

		Changes in LFP at		
O–INCOME	Slope	ADL = 6	ADL = 12	ADL = 18
5,000	−.020	−.12	−.24	−.36
10,000	−.016	−.10	−.19	−.29
20,000	−.008	−.05	−.10	−.14
30,000	.000	.00	.00	.00
40,000	.008	.05	.10	.14

As Table 6 shows, the slope of ADL on labor force participation for families with an annual income of $5,000 is −.020. This can be translated to a loss of 12% in the probability of employment at a level of disability that characterizes the average disabled child in two-parent families (i.e., ADL = 6). For mothers with a more severely disabled child, i.e., at one and two standard deviations above the mean, the likelihood of employment is reduced by 24% and 36%, respectively. For families with an annual income of $10,000, the slope is −.016 and the associated reductions in employment probabilities are smaller. For families with an annual income of $30,000, there is no linear relationship between level of disability and labor force participation, whereas for those with an income over $30,000, the regression slope is positive, indicating a positive impact on labor force participation of severity of disability. However, the reversal of the regression

TABLE 5. Hierarchical Regressions of Labor Force Participation and Hours of Work on Severity of Child Disability (ADL) by Marital Status* (partial unstandardized regression coefficients; standard error in parentheses)

	ADL	ADL × O–Income	ADL × Race
LFP			
Two-Parent Families	−.0236† (.0076)	.0008† (.0003)	−.0136 (.0107)
One-Parent Families	.0127 (.0148)	−.0025 (.0016)	.0063 (0155)
HOURS			
Two-Parent Families	−.5942† (.2036)		
One-Parent Families	−.4091 (.3000)		

* Controling for AGE, AGE², EDUCATION, CHILDREN, YOUNGEST and HEALTH. For HOURS regression, RACE and O–INCOME are also controlled.

† Coefficient exceeds twice its standard error.

sign is of little practical significance in this study, since most two-parent families with disabled children (92%) had an annual income of $30,000 or less. Indeed, the coefficient for ADL at entry into the regression (i.e., before the interaction terms were introduced), is statistically significant and negative, B = −.0101 (S.E. = .0039). The size of this average effect of ADL is approximately the same as that found for families with O-INCOME of $19,000, the median O-INCOME of two-parent families with disabled children. Thus, although severity of disability has a far greater impact on those at low incomes, it has a negative impact on the probability of employment of most married mothers.

The impact of severity of disability on the labor force participation of mothers in white two-parent families, as measured by the coefficient for ADL from which is partialled the effect of ADL × RACE, is statistically significant and negative (see Table 5). The negative slope for blacks is even steeper, −.0375, as compared to −.0236. The difference, although consistent with our expectation, is not statistically significant.

For single-parent families we did not find support for the interaction hypothesis; nor is there evidence that severity of child disability reduces maternal employment rate across incomes and racial groups.

In Table 5 appear also the regression of hours of work for working mothers on ADL for two-parent and single-parent families. With respect to hours of work, we hypothesized a weak negative main effect of disability measured either as a dichotomy or as a continuum of severity. As expected, coefficients for both groups are negative, and in two-parent families, the coefficient is statistically significant, as well. In single-parent families, the coefficient is larger than its standard error, but is not significant at $\alpha = .10$. Adding interaction terms, ADL × O-INCOME and ADL × RACE, to the equation of hours of work of either married or single mothers does not increase significantly the variance accounted for.

We infer from these findings that, as level of child disability increases, the number of work hours of employed wives decreases; and that this relationship is constant across income levels and between blacks and whites. Among two-parent families, when level of severity equals the mean of our sample with disabled children, a mother reduces her work week by approximately 3 hours. When the disability is at the maximum level of severity, she reduces her work week by 10 hours. For single mothers, corresponding reductions of hours of work are attenuated, and the negative impact itself is not statistically significant.

Summary of Results

The analysis presented in this paper provides evidence that caring for a disabled child in the home exerts a negative impact on the labor market behavior of married mothers. With respect to labor force participation, child disability interacts with race and income: it exerts a far greater negative impact on maternal labor force participation in black, as compared to white, families and reduces the probabilities of maternal labor force participation in families with income below the median, although increasing such probabilities in families with income above the median. The reduction in labor force participation is in direct relationship with severity of child disability. Although most families with disabled children are subject to the negative linear effect of severity, the amount of change in labor force participation associated with a unit change in severity is greater for families with a low income than for those with a high income. In contrast, the impact of child disability and severity on weekly hours worked by employed mothers is not conditioned by either family income or race. Family income has the same negative impact on hours of work of those with and without a disabled child, and employed black mothers work longer hours, independently of their children's health. Child disability has a weak negative main effect, if any, and the linear negative impact of severity of disability, while statistically significant, is, on the whole, modest.

These findings taken together confirm our expectations regarding the impact of child disability on families. Low-income and black wives, who must choose between the conflicting demands of continued employment and caring for a disabled child in the home, find themselves in an either/or situation: they either drop out of the labor market or continue to work longer hours, as compared to high-income and white mothers. Conversely, mothers in high-income and white two-parent families do not respond to the demands of care of a disabled child by leaving the labor force. In fact, the maternal employment probability in high-income families rises but, like employed mothers from high-income families and white families who do not have a disabled child, they are more likely to spend shorter hours at work.

Labor market activity of single mothers (i.e., widowed, divorced, separated or never married), does not appear to be significantly affected by child disability either alone or in interaction with income and race. The data suggest, however, that there may be a negative effect on labor force participation among white, single mothers.

Discussion

Our data are incomplete with respect to an important factor. Information on family income exclusive of mother's earning was not gathered from the sample of families of disabled children. In its absence, we estimated the value of this variable as a function of other variables. Although we have argued (with the support of empirical evidence) that the observed interaction between child disability and husband's income on maternal employment is unlikely to be the result of statistical bias, we could not rule this possibility out completely. Despite this limitation, the results warrant careful consideration, especially because the area of investigation has received little attention and is likely to be of increasing importance in the future.

An alternative explanation for the greater negative impact of child disability in black and low-income, two-parent families might be that these families have greater access to publicly supported medical care for their disabled children. According to this argument, mothers might reduce their labor force activity in order to qualify for these programs, or might feel less of a need for maternal earnings to pay for such services. The major public program supporting these special services is Crippled Children Services.* Forty-four percent of the two-parent families in this study receive such services. However, the employment rate among mothers of recipients is not different from that of mothers of nonrecipients, 40% and 46%, respectively. These data, and the fact that the Crippled Children Services program does not use a strict income-eligibility criterion, seem to rule out this alternate explanation.

Before one can fully assess the significance of our findings, it is necessary to take into account the economic conditions that induce black married women and wives of low-income husbands into the labor market in higher rates, and for longer hours. Low-income families are more likely to depend on wives' paid work for income needed for the purchase of nondiscretionary market goods (Organization for Economic Co-operation and Development, 1978). There is, however, a sharp contrast between the employment rates of black wives and those of white wives, a contrast that persists even when husband's income and other compositional differences are controlled. Several explanations have been offered for this discrepancy, such as race differences in marital instability, and in the availability of child care within the household and from relatives and friends outside the household (Cain, 1966; Sweet, 1973). Landry and Jendrek (1978) present data incompatible with these arguments. In their data, divorce rates were not higher among blacks, nor did black wives have a greater access to child care from family or friends. They suggest instead that, "black wives are not deterred from working by their husband's income for the simple reason that his income is not sufficiently high to allow them not to work" (Landrey and Jendrek, 1978:795). Put another way, black husbands' income is, on the average, below the threshold level at which it can have a deterrent effect upon the wives' labor force participation. In addition to these explanations, other factors should be considered. In this and in previous studies, husband's income was not measured with respect to either long-term earnings or the expected stability of his employment. The difficulty of maintaining a modest standard of living in unsettled economic times and in insecure jobs is probably greater for black than for white families. Such uncertainties may motivate black wives to remain in the labor market when white wives withdraw in response to increases in husband's income.

Since low-income and black families depend more closely on wives' earnings for their long-term standard of living, responsibilities that deter wives' employment are economically far more damaging for them than for other families. In high-income families, the withdrawal of the wife from market work reduces income, but the loss of this increment does not threaten the family's capacity to meet its basic needs. In low-income and black families, however, such losses often threaten the foundation of subsistance.

Our findings that a disabled child has no impact on the labor force activity of single mothers suggest the need for further research, as no one explanation could account for the negative results. One possible reason is that the sample of single mothers is less than one-third as large as that of the married mothers, so that rather small coefficients that would be statistically significant for married mothers are not so for single mothers. In addition, single mothers fall within a narrow income range, and the restricted variability may account for the insignificant conditional relationship between employment and disability by income. It is possible, however, that the uniformly low income of single mothers is of a substantive relevance as well: because single mothers and their children critically depend on income from the mothers' employment, they may be unable to make the economic sacrifice (i.e., to reduce their work week or drop out of the labor force) required for the extra care needs of a disabled child.[9]

Child disability has, in addition, non-economic effects on families. Previous reports indicate that mothers respond with depression and psychological distress (Breslau et al., 1980; Gayton et al., 1977; Tew and Laurence, 1973), and that some subgroups of normal siblings manifest behavior problems (Breslau et al., 1981; Lavigne and Ryan, 1979). Recent sociological research would lead us to expect, moreover, that these psychological responses may be more prevalent in lower class families. Sociological explanations of the inverse relationship between social class and psychiatric symptoms has focused chiefly on the function of stressful life events in this relationship. While research consistently indicates a higher rate of distress among the lower classes, it does not support the hypothesis that it is caused by the lower classes' greater exposure to stressful life events. Respondents in the lower classes have been found to exhibit more symptoms than do people in the higher classes at any given level of exposure to stressful experiences (Brown and Harris, 1978; Brown et al., 1975; Langner and Michael, 1963). Researchers have consequently postulated a differential emotional response to adverse life experiences of people in different social classes (Kessler, 1979; Kessler and Cleary, 1980).

It is unclear how intrapsychic and environmental factors interact and contribute to differential outcomes across social strata (Kessler and Cleary, 1980). The direct emotional consequences of adverse experiences in people in the lower classes is therefore problematic. The results of this study, emphasizing the differential economic impact of child disability between blacks and whites and across income levels, suggest a link between social class, psychological distress and the economic consequences of at least one category of adverse life experiences. They suggest that people in different social classes are experiencing and therefore perceiving different circumstances under what may, in the abstract, appear to be a single life event.

NOTES

1. With respect to several demographic characteristics (e.g., age, sex, level of education), Cuyahoga County resembles the Cleveland Urban Area (as defined by the Census) and the aggregate 248 Urban Areas containing 118,446,556 people, according to the 1970 Census. (U.S. Bureau of the Census, 1973). Cleveland is also similar to a number of other large eastern and midwestern metropolitan areas in terms of women's overall labor force participation rates. Data from the U.S. Bureau of Labor Statistics (Geographic Profile of Employment and Unemployment: States, 1978 and Metropolitan Areas, 1977–78) show, for women of ages 20 years and over, a rate of 45.2% in the Cleveland Standard Metropolitan Statistical Area. Rates for Buffalo, Baltimore, Cincinnati, Detroit, New York, Newark, Philadelphia, St. Louis and Pittsburgh SMSA's range from 42.0 to 50.5.
2. Analysis of data from the U.S. Census Bureau's Survey of Income and Education conducted by one of the authors (D.S.) shows higher rates of physical limitation in mothers of children with health problems than in those of children without health problems.
3. There are some statistical problems associated

with the use of a dichotomous dependent variable in ordinary least-squares (OLS) regression analysis (Goldberger, 1964). However, as alternate methods, such as probit analysis, have been shown to produce results that are not materially different from OLS (Gunderson, 1974; Mallar and Thornton, 1978), this latter analytic technique is used here. Note also that, as the final splits of the dichotomous dependent variables are approximately at midpoint, violating the assumptions in regression analysis may not have material consequences (Gillespie, 1977; Goodman, 1976).

4. On the basis of an extensive, critical review of published research, Ware et al. (1978) concluded that general health ratings, such as the one used here, are valid measures of health status. There is consistent evidence that these measures are associated with physical and mental health, use of medical services, and subsequent mortality.
5. Some researchers have suggested that a variable correcting for selectivity bias be included in regressions based only on data for employed women. (This variable is calculated by estimating a multiple probit regression based on all women with employment status as the dependent variable.) Cogan has reported, however, that results obtained by the procedure used here are quite similar to those obtained with a selection bias variable included (See Cogan, 1977).
6. This scale was modeled after the Impact on Family Scale developed by Stein and Riessman (1980).
7. Further support for this interpretation is provided by a cross-tabulation of employment status and occupation status of mothers in the two samples. For those in white-collar occupations, there is no significant difference in employment rate between the two samples, whereas for those in blue-collar occupations, mothers of disabled children are less likely to be employed (Chi square = 2.80, $p < .10$).
8. This program supports the provision of specific medical services for children with particular chronic conditions; however, it does not provide any cash payments directly to families.
9. The mean annual income exclusive of mother's earnings in single-parent families in this study was less than $5,000. Government data cited by Sawhill (1976) suggest that single-parent families headed by a woman have become uniquely disadvantaged. In 1973, the average annual income of such families was $6,000, as compared to $15,000 for two-parent families. Other data indicate that almost half of all families headed by women with children are poor, and that a majority of all poor families with children are now headed by women.

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Use of Health Services by Chronically Ill and Disabled Children

KATHLEEN SMYTH-STARUCH, MA,* NAOMI BRESLAU, PHD,†
MICHAEL WEITZMAN, MD,‡ AND STEVEN GORTMAKER, PHD§

Hospitalization and use of outpatient health care services during a 1-year period by 369 pediatric patients with cystic fibrosis, cerebral palsy, myelodysplasia, or multiple physical handicaps and 456 randomly selected children without congenital conditions from the Cleveland area were examined. Use of hospitalization and outpatient services by the average chronically ill or disabled child was 10 times that of the average comparison child. Physician specialists, occupational and physical therapists, and school nurses were the major outpatient categories used disproportionately by children with chronic illnesses or disabilities. The major share of health care used by children with chronic conditions was attributable to a small subset of children: All hospital care was accounted for by one third of the children, and three quarters of all outpatient care was accounted for by one quarter of that sample. Hospital care was used at similar rates by the four diagnostic groups. However, amount and type of outpatient care varied by diagnosis, level of functional impairment, race, and income. Estimated average expenditure for health services used by the chronically ill or disabled sample was 10 times that of the comparison sample. Relative distribution of estimated expenditures across types of services differed for the two samples as well as among diagnostic categories.

Key words: childhood chronic illness; utilization; health care; hospitalization. (Med Care 1984, 22:310–328)

Children are the healthiest segment of the American population. Although the incidence of acute illness is high, few children suffer from chronic illness or disability, and their overall mortality is low. Because of their excellent health, children use far less inpatient medical care than adults. The average child spent only 29% as many days in the hospital in 1975-76 as an adult younger than 65 years of age and only 8% as many days as an individual 65 years of age or older.[1] For most children medical care consists of visits to office-based physicians for routine preventive care and for the treatment of acute illness. Even with respect to ambulatory medical care, children use fewer services than adults. In 1975-76, the average child younger than 17 years of age had 4.1 physician contacts, while on the average, adults 18–64 years of age had 5.2 and those 65 years of age and older had 6.7.[1]

Although children with physicial limitations constitute a small proportion of the noninstitutionalized child population,

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* From the Department of Epidemiology and Community Health, Case Western Reserve University, School of Medicine, and Veterans Administration Medical Center, Cleveland, Ohio.

† From the Department of Epidemiology and Community Health, Case Western Reserve University, School of Medicine, Cleveland, Ohio.

‡ From Boston University School of Medicine, Boston, Massachusetts.

§ From Harvard School of Public Health, Boston, Massachusetts.

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Address correspondence to: Kathleen Smyth-Staruch, MA, Department of Epidemiology and Community Health, Case Western Reserve University, School of Medicine, Cleveland, OH 44106.

their use of health care is markedly disproportionate to their numbers. Recent statistics from the United States National Health Interview Survey (NHIS)[2] indicate that in 1979 children with activity limitation due to chronic illness constituted 3.9% of the child population younger than 17 years of age, but accounted for more than 30% of hospital days used by the total cohort. The average annual number of hospital days for a child with activity limitation was 2.8, compared with 0.3 for a child free of limitation. Physician visits were also more frequent among disabled children than the general child population: The average annual number of physician visits for a child with activity limitation during 1979 was 9.5, compared with 3.9 for a child without limitation. In spite of its importance for health care policy and planning, information on the use of rehabilitation, mental health, and social services by chronically ill or disabled children is not available from the NHIS.

A survey of physicians in Genesee County, New York, revealed that public health nurses, social workers, mental health workers, physiotherapists, and vocational rehabilitation specialists were rarely used for the six disabling conditions (asthma, epilepsy, heart disease, arthritis, diabetes, and cerebral palsy) covered in that survey.[3] While the report emphasized the overwhelming needs of children with disabilities and the failure of existing health programs to meet them, it did not document the types and volume of services these children actually used. In a recent assessment of the state of knowledge about children with special needs, Pless and Zvagulis concluded that most pertinent epidemiologic data are deficient with regard to utilization of medical and related services.[4]

While we know that children with chronic conditions as a group are more likely than children without such conditions to use health care services and to do so more frequently, and that volume of use varies within this group as well, our knowledge is still incomplete. Whether and to what extent elements intrinsic to a particular disability, severity of functional impairment, and socioeconomic factors influence this variation merit study.[2] Type of condition and severity might be conceptualized as indicators of need for various medical and rehabilitative services. The extent to which these variables account for variation in services used might be regarded as a measure of equity in health care. In contrast, an association between utilization and socioeconomic factors might be an index of inequity.

In this paper, we report on health services used by children with chronic congenital conditions who receive care in specialty clinics in Cleveland, Ohio. We examine the use of services by these children as a group, as well as by four diagnostic categories—cystic fibrosis, myelodysplasia (spina bifida), cerebral palsy, and multiple physical handicaps (multiple congenital disorders, all with physical stigmata, some of which are identifiable as specific syndromes). Although strictly speaking the data are not generalizable [illegible] the entire population of children with chronic illness or disability, the four conditions represent a range of congenital physical abnormalities involving various organ systems and different levels of severity. In addition, cerebral palsy, myelodysplasia, and cystic fibrosis constitute three of the more common severe chronic conditions of childhood. The prevalence of cystic fibrosis, cerebral palsy, and myelodysplasia in the United States totals about 0.5%.[5] Prevalence rates for multiple handicaps are not available because it is a heterogeneous group of rare physical conditions. United States NHIS data from 1979 indicate that 3.9% of children 0–16 years of age have limitation of activity due to chronic conditions.[6] The national data refer only to children with chronic conditions who are limited in their activities, and thus exclude, for example, those children with cystic fibrosis who function normally in school. These estimates indicate, however, that the diagnostic groups in the present study constitute approximately one eighth of children with serious chronic diseases and conditions.

Our approach was comprehensive, and an attempt was made to cover all health and related services used on behalf of the affected children. This report, therefore, is not confined only to hospital care and physician services, but describes also the use of dentists, nurses, rehabilitation workers, counselors, social workers and mental health professionals, nutritionists, and a variety of other providers. For comparison, we present utilization data from a randomly selected sample of 456 children free of chronic illness or disability.

The objectives of this research are: (1) to describe the use of health services by these children; and (2) to investigate empirically whether and to what extent use of services was related to type of condition, severity of impairment, and socioeconomic factors.

For each service used we describe the proportion of children using the service, the mean use by children who received the service, and the mean use across all children—those who received the service and those who did not. These data are examined separately by diagnostic category as well as for the total group of chronically ill and disabled children. The same data are also reported for the comparison sample. We then employ multivariate statistical techniques to estimate the degree to which socioeconomic variables—race, family income, and mother's education—influence the use of health services by children with varying chronic conditions and varying levels of severity.

Sample and Data

Families of children with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps were selected from the case loads of four pediatric specialty clinics in two teaching hospitals in Cleveland, Ohio. The majority of children with these severe conditions are referred to tertiary medical institutions. The participating hospitals are two of the three tertiary hospitals in the Cleveland area, and their clinics' case loads provide relatively representative samples of area children in these diagnostic categories. A detailed description of these clinics and their populations is available elsewhere.[7,8] All Cleveland-area families of patients 3–18 years of age with these diagnoses who had had a clinic visit within the last 2 years were asked to participate in the study. Interviews were obtained from 369 (80%) of the 460 eligible families. This sample included 77 families with a child with cystic fibrosis (CF) receiving care from a clinic specializing in the treatment of cystic fibrosis patients; 118 families with a child with cerebral palsy (CP) who received care at either a cerebral palsy–orthopedic clinic, or a comprehensive care clinic serving children with physical handicaps of various types; 92 with myelodysplasia (MY) who were patients at either the comprehensive care clinic or myelodysplasia–hydrocephalus clinic; and 82 with multiple physical handicaps (MH) who were seen at the comprehensive care clinic.

To obtain a comparison group, we designed a three-stage probability sample to represent all Cleveland-area families with children 3–18 years of age. (With respect to several demographic characteristics—age, sex, and level of education—the Cleveland Urban Area (as defined by the Census) resembles the aggregate 248 urban areas containing 118,446,556 people, according to the 1970 Census (United States Bureau of the Census).) The selection of a random sample of the general population avoids the problems that characterize studies with matched controls, in which many known as well as unknown confoundings are necessarily left uncontrolled. Further, our sampling scheme produced a representative sample of the general population (i.e., a normative sample), rather than an idiosyncratic sample of indeterminate generalizability, as might be the case when controls are matched. When a probability sample is used, matching is accomplished statistically in the analysis. A detailed description of the sampling scheme appears elsewhere.[9] From 530 eligible families, 456 (86%) complete interviews were obtained. In each family, a randomly selected child 3–18 years of age was defined as the index child and was the focus of an extensive inquiry comparable to that of the disabled or chronically ill child.

Data were gathered from mothers in face-to-face, home interviews conducted in 1978-79. Detailed information was gathered on the index child's use of a variety of health care services during the year prior to the interview. With regard to hospitalization, mothers were asked to report on the number of overnight hospitalizations the child had had and the length of stay for each episode. Data on the use of ambulatory services were gathered by using a list of health care practitioners and asking the respondents whether and how often each had been seen by the child or on the child's behalf in the year prior to the interview. The list of practitioners included physician, dentist, nurse, social worker, child and family counselor, speech, occupational and physical therapist, and dietician or nutritionist. (Mothers of chronically ill or disabled children, but not of controls, were asked about the use of residential and respite care, genetic counselor, and homemaker and legal services. Less than 2% of the children in this sample used any of these services.)

Research sponsored by the National Center for Health Statistics indicates that underreporting of hospitalizations in household surveys increases with the length of time between interview and hospitalization: 9% of hospitalizations, for example, were found not reported given 21–30 weeks between the hospitalization and the interview.[10] A Canadian study linked household survey data with reimbursement reports and found underreporting of any doctor visits during the past year to be about 16%.[11] Thus, levels of utilization described in the present report probably underestimate "true" utilization by comparable amounts. Although some differences in reporting accuracy have been noted between respondents in good and poor health,[12] we expect that comparisons between groups will not be substantially affected by these generally small biases. Comparing our results with childrens' medical records clearly would have enhanced our confidence in the reports we recorded. Because our analysis includes all health care services used by the index child, however, comparing our results to the specialty clinic and hospital records to which we had access would have provided only a partial test of reliability and would have focused on that portion of utilization data in which we have the highest confidence. Records of use of services by the disabled children outside the hospital and specialty clinic were not available to us. Further, because our comparison sample was not obtained from medical records, we did not have access to comparable medical record data for these children.

Results

Hospitalization

Disabled or chronically ill children, regardless of diagnosis, were far more likely to be hospitalized during the year of the study than controls (34% and 6%, respectively) ($P < 0.001$) (Table 1). Differences across diagnosis were slight. Annual number of hospital days for those hospitalized was, on the average, at least two times greater for each diagnostic group than for controls. The mean number of days for children with chronic conditions who were hospitalized was 17.3, whereas for

TABLE 1. Hospitalization: Percent (n) Hospitalized in Last Year, Means, and Standard Deviations

	CF (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
% Hospitalized	31.2 (24)	29.7 (35)	36.5 (30)	38.0 (35)	33.9 (124)	6.1 (28)
		$\chi^2 = 2.4$			$\chi^2 = 104.3^a$	
Hospitalized						
$\overline{X}$	13.2	23.2	15.9	15.3	17.3	6.2
SD	7.3	45.0	16.5	21.2	27.8	6.7
		$F = 0.78$			$t = 2.1^b$	
All cases						
$\overline{X}$	4.2	6.9	5.8	5.8	5.8	0.4
SD	7.4	26.5	12.5	15.0	18.0	2.2
		$F = 0.34$			$t = 6.4^a$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.
SD, standard deviation.
[a] $P < 0.001$.
[b] $P < 0.01$.

the controls it was 6.2 ($P < 0.01$). Average length of stay (per hospitalization) for disabled or chronically ill children was 11.0 days, compared with 3.7 days for controls. There were only small fluctuations in average length of stay across diagnostic categories (data not shown). Between 3% and 5% of children with CP, MY, and MH reported 1 or more days in intensive care. There were no such episodes among children with CF, however, and less than 1% of the controls had been in intensive care (data not shown). Averaging over all cases, those with and without hospitalizations, a disabled or chronically ill child had 5.8 hospital days during the year, whereas a control child had 0.4.

Physician Visits

Although most children saw a physician during the year prior to the interview, more children with chronic conditions than controls had physician visits (98% and 88%, respectively) ($P < 0.001$) (Table 2). An examination of the generalist/specialist breakdown reveals a more complex pattern. The proportion of the total disabled or chronically ill sample who saw a generalist (i.e., pediatrician, general practitioner, internist, or emergency room doctor) was virtually identical to that of controls (77% and 76%, respectively). In contrast, the proportion of the total sample with chronic conditions who saw specialists was nearly twice that of the controls (79% and 42%, respectively) ($P < 0.001$).

The expected higher level of use of physician services by children with chronic conditions is far more evident when volume of visits is examined. When calculated over all children, including those with no visits during the year, the average number of visits to all physicians made by disabled or chronically ill children was nearly three times that made by controls (8.9 and 3.3, respectively) ($P < 0.001$). The disparity between the two samples was far greater in visits to specialists than generalists.

Table 2 reveals striking differences in the volume of physician visits across the four conditions as well. Children with CF visited physicians more often than any other diagnostic group. Their higher level of physician visits was because of an extensive use of specialists, which, at 9.8 visits per year, was significantly higher than the use of specialists by any of the other three

TABLE 2. Physician Visits: Percent (n) Who Visited a Physician in Last Year, Means, and Standard Deviations

	CF (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
All physicians[a]						
% with use	100.0 (77)	99.2 (117)	98.8 (81)	93.5 (86)	97.8 (361)	88.4 (403)
		$\chi^2 = 30.1^b$			$\chi^2 = 26.6^b$	
Users						
$\bar{X}$	11.3	6.6	10.5	9.3	9.1	3.8
SD	4.2	6.1	10.5	14.9	9.8	5.5
		$F = 4.5^c$			$t = 9.1^b$	
All cases						
$\bar{X}$	11.3	6.5	10.4	8.7	8.9	3.3
SD	4.2	6.1	10.5	14.6	9.8	5.3
		$F = 4.6^c$			$t = 10.2^b$	
Generalists[d]						
% with use	35.1 (27)	83.9 (99)	91.5 (75)	89.1 (82)	76.7 (283)	76.5 (349)
		$\chi^2 = 95.8^b$			$\chi^2 = 0.0$	
Users						
$\bar{X}$	3.9	4.1	3.8	5.2	4.3	2.3
SD	4.7	5.2	3.3	6.7	5.2	2.8
		$F = 1.1$			$t = 5.4^b$	
All cases						
$\bar{X}$	1.3	3.4	3.5	4.6	3.3	2.0
SD	3.3	5.0	3.3	6.5	4.9	2.5
		$F = 6.6^b$			$t = 5.0^b$	
Specialists						
% with use	93.5 (72)	83.1 (98)	87.8 (72)	55.4 (51)	79.4 (293)	41.7 (190)
		$\chi^2 = 150.8^b$			$\chi^2 = 119.7^b$	
Users						
$\bar{X}$	10.4	3.6	7.8	6.7	6.9	3.3
SD	3.6	2.5	8.0	13.3	7.6	6.6
		$F = 13.1^b$			$t = 5.0^b$	
All cases						
$\bar{X}$	9.8	3.0	6.8	3.6	5.4	1.3
SD	4.4	2.7	7.9	10.3	7.3	4.4
		$F = 18.6^b$			$t = 10.0^b$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.

SD, standard deviation.

[a] Includes generalists and specialist categories as well as physicians who could not be classified as generalists or specialists.

[b] $P < 0.01$.

[c] $P < 0.001$.

[d] Includes general pediatricians, general practitioners, internists, and emergency room doctors.

diagnostic groups ($P < 0.05$, using Scheffé comparisons). This pattern was reversed for generalists, with children with CF having a significantly lower mean than each of the other diagnostic groups.

More than 50% of the chronically ill or disabled children visited physicians at both the specialty clinic and other locations. For 32%, ambulatory medical care was provided exclusively by clinic physicians, while 14% saw doctors only in settings other than the specialty clinics. An examination of the volume of physician visits by site reveals that approximately 70% of all physician visits made by children with chronic conditions were at the specialty clinics in which they were enrolled (data not shown).

Dental Visits

The proportion of disabled or chronically ill children who saw a dentist in the year prior to the interview was only slightly lower than that of controls (61% and 69%, respectively) (Table 3). The difference was, however, statistically significant ($P < 0.01$). Important differences were observed across conditions. Children with CF were the most likely to see a dentist and children with MY the least likely (83% and 44%, respectively). Mean annual visits did not differ significantly between children with chronic conditions and controls (1.8 and 2.5, respectively) (Table 3).

Rehabilitation Services: Occupational, Physical, and Speech Therapy

The use of occupational, physical, and speech therapist services by children with chronic conditions as a group was markedly higher than by controls (Table 4). For each type of service, differences in the percent of users and in the mean number of services were statistically significant ($P < 0.001$).

The four diagnostic groups varied markedly in the proportion who used rehabilitation services and in the amounts used (Table 4). The major disparity was between children with CF, who rarely saw these therapists, and children in the remaining three diagnostic groups, who saw them more frequently.

A comparison of the diagnostic categories other than CF reveals that children with CP and MY were quite similar in their use of occupational and physical therapists: in each group, nearly 40% used occupational therapists, and over 60% used physical therapists. Proportionally fewer children with MH used occupational and physical therapists (16% and 37%, respectively). However, differences in the volume of use for those who used these services across the three diagnostic groups were not statistically significant.

Use of speech therapists was twice as common among children with CP and MH than among those with MY. Differences in the mean number of services for users were not statistically significant, however.

Mental Health/Social Service

Disabled or chronically ill children were nearly five times as likely as controls to use mental health or social service during the year (36% and 8%, respectively) ($P < 0.001$)

TABLE 3. Dental Visits: Percent (*n*) Who Had Dental Visits in Last Year, Means, and Standard Deviations

	CF (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
% with use	83.1 (64)	57.6 (68)	43.9 (36)	62.0 (57)	61.0 (225)	69.3 (316)
		$\chi^2 = 26.5^*$			$\chi^2 = 6.2^\dagger$	
Users						
$\bar{X}$	3.2	3.0	2.8	3.0	3.0	3.6
SD	2.9	4.5	3.1	5.0	4.0	7.0
		$F = 0.0$			$t = -1.1$	
All cases						
$\bar{X}$	2.6	1.8	1.2	1.8	1.8	2.5
SD	2.9	3.7	2.5	4.2	3.5	6.0
		$F = 2.2$			$t = -1.83$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.

[*] $P < 0.001$.

[†] $P < 0.01$.

TABLE 4. Rehabilitation Services: Percent (n) Who Used Services in Last Year, Means, and Standard Deviations

	CF (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
Occupational therapist						
% with use	— (0)	39.0 (46)	37.8 (31)	16.3 (15)	24.9 (92)	— (0)
		$\chi^2 = 48.9^*$			$\chi^2 = 128.0^*$	
Users						
$\bar{X}$	—	59.7	43.3	45.6	51.8	—
SD	—	66.1	52.3	65.0	61.1	—
		$F = 0.7$				
All cases						
$\bar{X}$	—	22.0	16.0	6.1	12.0	—
SD	—	49.2	37.9	27.8	36.6	
		$F = 7.0^*$				
Physical therapist						
% with use	7.8 (6)	66.1 (78)	61.0 (50)	37.0 (34)	45.5 (168)	0.7 (3)
		$\chi^2 = 75.0^*$			$\chi^2 = 249.9^*$	
Users						
$\bar{X}$	62.2	54.3	60.6	43.0	54.0	14.3
SD	148.4	57.2	55.4	55.6	55.9	12.1
		$F = 0.5$			$t = 1.1$	
All cases						
$\bar{X}$	4.8	35.2	36.6	14.7	24.0	0.1
SD	41.6	52.8	52.3	38.1	48.8	1.4
		$F = 9.5^*$			$t = 10.5^*$	
Speech therapist						
% with use	9.1 (7)	45.8 (54)	22.0 (18)	50.0 (46)	33.9 (125)	3.7 (17)
		$\chi^2 = 44.4^*$			$\chi^2 = 130.1^*$	
Users						
$\bar{X}$	26.4	53.2	[illegible]	62.5	54.4	29.2
SD	27.3	54.7	45.6	63.7	61.2	35.4
		$F = 1.0$			$t = 1.7$	
All cases						
$\bar{X}$	2.4	23.6	9.8	29.5	17.4	1.1
SD	10.8	44.9	28.0	53.6	40.5	8.6
		$F = 8.4^*$			$t = 8.3^*$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.
SD, standard deviation.
* $P < 0.001$.

(Table 5), but volume of services used by those who had at least one visit was, on the average, similar in the two samples (9.4 and 8.3, respectively). As a consequence of these trends, children with chronic conditions, as a group, had a significantly higher mean use than controls (3.3 and 0.6, respectively) ($P < 0.001$). Social workers constituted the most common source of services of this sort for disabled or chronically ill children, but were rarely used by controls: 30% of children with chronic conditions but only 1% of controls received services from social workers. When children in the control group saw professionals in the mental health-social service field, they saw primarily counselors (e.g., school counselors, child and family counselors). Psychiatrists and psychologists were seen by very few children (2%) from either sam-

TABLE 5. Mental Health/Social Service: Percent (n) Who Used Services in Last Year, Means, and Standard Deviations

	CE (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
Total mental health/social service						
% with use	10.4 (8)	36.4 (43)	47.6 (39)	47.8 (44)	36.3 (134)	7.7 (35)
	$\chi^2 = 32.1^a$				$\chi^2 = 102.7^a$	
Users						
$\bar{X}$	2.6	13.8	7.2	8.1	9.4	8.3
SD	1.5	31.4	10.6	14.3	20.5	17.8
	$F = 1.1$				$t = 0.3$	
All cases						
$\bar{X}$	0.2	5.0	3.4	3.8	3.3	0.6
SD	0.9	19.8	8.1	10.6	13.0	5.0
	$F = 2.1$				$t = 4.2^a$	
Psychiatrist/psychologist						
% with use	1.3 (1)	0.8 (1)	3.7 (3)	3.3 (3)	2.2 (8)	1.5 (7)
	$\chi^2 = 2.6$				$\chi^2 = 0.4$	
Users						
$\bar{X}$	3.0	12.0	12.3	16.3	12.6	2.0
SD	—	—	17.0	17.9	13.9	1.4
	$F = 0.1$				$t = 2.0$	
All cases						
$\bar{X}$	0.04	0.1	0.4	0.5	0.27	0.03
SD	0.3	1.1	3.5	3.9	0.26	0.3
	$F = 0.8$				$t = 1.9^b$	
Counselor[c]						
% with use	2.6 (2)	13.6 (16)	8.5 (7)	14.1 (13)	10.3 (38)	5.7 (26)
	$\chi^2 = 8.0^b$				$\chi^2 = 6.0^d$	
Users						
$\bar{X}$	2.5	6.6	12.4	7.2	7.7	9.8
SD	0.7	11.0	13.8	13.9	12.2	20.4
	$F = 0.5$				$t = 0.5$	
All cases						
$\bar{X}$	0.1	0.8	1.1	1.0	0.8	0.5
SD	0.4	4.4	5.1	5.6	4.5	5.0
	$F = 0.8$				$t = 0.8$	
Social worker						
% with use	7.8 (6)	28.8 (34)	42.7 (35)	38.0 (35)	29.8 (110)	0.9 (4)
	$\chi^2 = 27.4^a$				$\chi^2 = 143.4^a$	
Users						
$\bar{X}$	2.0	14.3	4.4	6.0	7.8	5.7
SD	1.2	33.0	6.1	9.8	19.8	5.5
	$F = 1.8$				$t = 0.3$	
All cases						
$\bar{X}$	0.1	4.0	1.9	2.2	2.3	0.04
SD	0.6	18.5	4.5	6.6	11.2	0.06
	$F = 1.9$				$t = 4.3^a$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.
SD, standard deviation.

[a] $P < 0.001$.

[b] $P < 0.05$.

[c] Includes school psychologists and school, vocational, child, family, and unspecified counselors.

[d] $P < 0.01$.

ple. (Psychiatrists and psychologists did not appear as separate categories on our list of practitioners. When mothers reported use of a physician or counselor, we asked for the specific type. This method might result in an underestimation of use of these services.)

The use of mental health and social services varied by diagnostic category. Approximately 40% of children with CP, MY, and MH, compared with 10% of children with CF, used these services. Further, the volume of mental health and social services used by children with CF (when calculated over all cases) was not significantly different from controls: for both, it was less than one visit. For each of the remaining conditions, average use was significantly higher than for either the controls or the CF group. It should be noted, however, that when users of services are compared, differences between the disabled or chronically ill children and controls and across diagnostic categories are not statistically significant. This is the case for total use of mental health or social services as well as for each category of practitioner.

Other Health-Related Services

Between 42% and 59% of school children in the four diagnostic groups and controls had some contact with a school nurse in the year preceeding the interview (Table 6). The proportion of children who saw the school nurse did not vary significantly between controls and disabled or chronically ill children as a group or by type of condition. Amount of use, however, was significantly higher for those with chronic conditions: when users are compared, controls averaged 2.1 visits, while chronically ill or disabled children averaged 29.4 ($P < 0.001$). When calculated as means for all cases, the figures are 0.8 and 13.1, respectively ($P < 0.001$). Differences across the means of the four diagnostic groups were not significant.

Disabled or chronically ill children were more than five times as likely as controls to have a contact with other nurses, including office nurse, nurse practitioner, and public health nurse (28% and 5%, respectively) ($P < 0.001$). Differences by diagnosis were also marked: 12% of CF patients compared with 55% of MY patients reported contact with a nurse in this category. The average number of nurse services for disabled or chronically ill children who used the services was only slightly and not significantly higher than for controls who were users (3.5 and 2.7, respectively).

A very small proportion of children with chronic conditions (4%) used dietician or nutritionist services; this proportion is, however, significantly higher than the 1% of the controls who used these services ($P < 0.001$).

Total Services

Nearly every child in both the disabled or chronically ill and control samples used health care services during the year prior to the interview (99% and 97%, respectively) (Table 7). The slight difference in these proportions is, however, statistically significant ($P < 0.01$).

With respect to volume of services used during the previous year, chronically ill or disabled children surpassed the controls approximately 10-fold: mean number of services used by children with chronic diseases was 78.8, compared with 7.8 for controls ($P < 0.001$). There were also striking differences by diagnosis. Children with CP and MY were the highest users, with nearly identical means of approximately 100. These figures are significantly higher than the means of children with CF and MH (34.7 and 68.5, respectively) ($P < 0.01$). The difference between the latter two groups is also statistically significant ($P < 0.01$, Scheffé comparisons) (Table 7).

The marked differences between children with and without chronic conditions that emerged from the comparisons in Ta-

TABLE 6. Other Health-Related Services: Percent (n) Who Used Services in Last Year, Means, and Standard Deviations

	CE (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls (456)
School nurse[a]						
% with use	41.5 (27)	49.0 (51)	49.3 (35)	58.8 (30)	46.7 (163)	43.9 (176)
		$\chi^2 = 4.6$			$\chi^2 = 2.8$	
Users						
$\bar{X}$	34.6	35.6	39.1	12.2	29.4	2.1
SD	68.0	68.3	76.0	39.4	63.2	2.3
		$F = 1.6$			$t = 5.2^b$	
All cases						
$\bar{X}$	13.4	15.5	17.1	6.5	13.1	0.8
SD	45.0	48.2	53.5	29.2	44.7	1.8
		$F = 0.8$			$t = 5.3^b$	
Other nurses[c]						
% with use	11.7 (9)	16.9 (20)	54.9 (45)	31.5 (29)	27.9 (103)	5.3 (24)
		$\chi^2 = 47.3^b$			$\chi^2 = 80.3^b$	
Users						
$\bar{X}$	6.2	1.8	3.7	3.6	3.5	2.7
SD	8.8	1.3	3.7	3.7	4.1	2.6
		$F = 2.5$			$t = 0.9$	
All cases						
$\bar{X}$	0.6	0.3	2.0	1.1	1.0	0.1
SD	3.3	0.9	3.2	2.6	2.6	0.8
		$F = 7.4^b$			$t = 6.3^b$	
Dietician/nutritionist						
% with use	2.6 (2)	6.8 (8)	2.4 (2)	15.2 (14)	3.9 (32)	1.3 (6)
		$\chi^2 = 14.4^d$			$\chi^2 = 18.0^b$	
Users						
$\bar{X}$	2.0	2.6	2.5	5.2	3.8	5.7
SD	1.4	1.6	2.1	10.3	7.2	3.2
		$F = 0.2$			$t = 0.6$	
All cases						
$\bar{X}$	0.1	0.2	0.1	0.6	0.2	0.1
SD	0.4	0.5	0.4	3.9	2.0	0.7
		$F = 0.8$			$t = 1.6$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap; SD, standard deviation.

[a] For children in school only (patients, n = 325; controls, n = 401).

[b] $P < 0.001$

[c] Includes office nurse, nurse practitioner, and public health nurse.

[d] $P < 0.01$

bles 1–7 remained unaltered when sociodemographic factors were controlled, as additional analysis showed. When family size, income, mother's education, race, and age of the child were used as covariates, adjusted means of disabled children and controls varied from the unadjusted means depicted in Tables 1–7 by no more than one. Analyses of covariance of each type of service use by the four diagnostic groups, using the same set of sociodemographic variables as covariates, resulted in adjusted means that did not differ substantially from the unadjusted means. In no case did the adjustment alter the rank order of the four groups.

TABLE 7. Total Services: Percent (n) Who Used Any Service in Last Year, Means, and Standard Deviations

	CF (77)	CP (118)	MY (82)	MH (92)	Patients (369)	Controls 456)
% with use of any services	100.0 (77)	99.2 (117)	100.0 (82)	98.9 (91)	99.5 (367)	97.1 (443)
		$\chi^2 = 6.1$			$\chi^2 = 6.1^*$	
Users						
$\bar{X}$	35.1	100.2	102.2	71.2	79.3	8.1
SD	63.0	146.6	136.7	121.0	126.1	13.2
		$F = 4.8^*$			$t = 11.0^*$	
All cases						
$\bar{X}$	34.7	98.5	101.4	68.5	78.8	7.8
SD	62.5	145.9	134.8	119.7	125.8	13.0
		$F = 4.8^*$			$t = 11.1^*$	

CF, cystic fibrosis; CP, cerebral palsy; MY, myelodysplasia; MH, multiple physical handicap.
SD, standard deviation.
* $P < 0.01$.
* $P < 0.001$.

The Distribution of Health Care Among Disabled Children

While chronically ill or disabled children as a group are heavy utilizers of medical and other health-related services, their level of use is far from constant. That this is true can be seen from the preceding tables. With respect to days of hospitalization and every type of health practitioner studied, there was a proportion of chronically ill children with no use of services at all. Further, the standard deviations were generally high, often exceeding their respective means.

The distribution of inpatient hospital days and ambulatory services and the extent to which they were concentrated within a fraction of disabled or chronically ill children was examined by ordering the sample according to frequency of each type of use and dividing it into quartiles. Table 8 presents means, standard deviations, and ranges for each quartile. It also presents the utilization by the highest quartile, measured as a proportion of the total services used by the entire sample. Distributions for controls are included for comparison. Data are presented for those services used by 25% or more of both samples.

Nearly all hospital days used by the chronically ill or disabled children (96%) were used by one quarter of that sample; among controls, one quarter of the sample accounted for all hospital days. Concentration of ambulatory services in a small proportion of children is evident for both children with chronic conditions and controls. More than 50% of physician visits made by all of the chronically ill or disabled children and more than 60% of those made by controls were accounted for by one quarter of the respective samples. Three quarters of dentist visits of each of the samples were likewise concentrated in one quarter of the cases. For school nurse visits, one quarter of each sample accounted for 98% and 88% of the total use made by patient and controls samples, respectively. Over all, 75% of outpatient health care used by children with chronic conditions and 65% used by controls were attributable to one quarter of the respective samples. The greater concentration of total services among children with chronic conditions compared with controls reflects that this

Table 8. Services Received in Last Year by Chronically Ill and Disabled Children and Controls: Quartile Distributions

Service	Patients (369)					Controls (456)				
	1st Q	2nd Q	3rd Q	4th Q	Total	1st Q	2nd Q	3rd Q	4th Q	Total
Hospital										
Mean days	0.0	0.0	0.94	22.4	6.5	0.0	0.0	0.0	1.5	0.4
Range	0–0	0–0	0–5	5–238	0–238	0–0	0–0	0–0	0–34	0–34
% of total received by 4th quartile				96					100	
Physician										
Mean visits	2.1	5.2	9.0	19.3	8.9	0.5	1.5	2.7	8.5	3.3
Range	0–4	4–7	7–11	11–113	0–113	0–1	1–2	2–4	4–59	0–59
% of total received by 4th quartile				54					64	
Generalist										
Mean visits	0.1	1.5	2.8	8.9	3.3	0.1	1.0	1.9	4.9	2.0
Range	0–1	1–2	2–4	4–42	0–42	0–1	1–1	1–3	3–24	0–24
% of total received by 4th quartile				67					61	
Specialist										
Mean visits	0.2	2.2	5.8	13.6	5.4	0.0	0.0	0.5	4.5	1.3
Range	0–1	1–4	4–8	8–87	0–87	0–0	0–0	0–1	1–58	0–58
% of total received by 4th quartile				62					87	
Dentist										
Mean visits	0.0	0.4	1.4	5.5	1.8	0.0	0.8	1.6	7.6	2.5
Range	0–0	0–1	1–2	2–36	0–36	0–0	0–1	1–2	2–104	0–104
% of total received by 4th quartile				75					76	
School nurse[a]										
Mean visits	0.0	0.0	1.0	51.3	13.1	0.0	0.0	0.6	2.8	0.8
Range	0–0	0–0	0–2	2–260	0–260	0–0	0–0	0–1	1–15	0–15
% of total received by 4th quartile				98					88	
Total practitioners										
Mean visits	6.5	17.2	52.2	239.0	78.8	1.4	3.5	6.0	20.2	7.8
Range	0–11	11–26	26–94	94–832	0–832	0–3	3–4	4–8	8–119	0–119
% of total received by 4th quartile				76					65	

[a] For school children only.

Q, quartile.

total includes rehabilitation and mental health services, which were used more often by them than by controls and were characterized by markedly unequal use.

The Determinants of Use of Health Care Services

We examined next the determinants of use of health services by children with chronic conditions. To what extent does use reflect need and to what extent does it reflect differential access to services due to socioeconomic factors?

To explore this question, we performed a series of multiple regressions in which use was regressed on diagnostic category and severity of disability (ADL) (assumed to be indicators of need) and on mother's education, family income, and race (assumed to be indicators of socioeconomic status). Age and sex of the child, mother's marital and employment status, and number of children in the household were also included to control for their effects. (See Table 9 for the coding of each predictor and control variable.)

If use of services is related to need independent of socioeconomic status (SES), we would expect the coefficients for diagnosis and for ADL to be significant. To the extent that socioeconomic factors are influential, we would expect mother's education, family income, and race to have significant coefficients. Results of this analysis are presented in Table 9.

For those services used by fewer than three fourths of the total sample with chronic conditions, analysis was in two steps. In the first regression probability of being a user (1 = user, 0 = nonuser) and in the second regression volume of use by users were the dependent variables. Because nearly all children saw a physician during the year of the study, only one regression was performed, with number of visits as the dependent variable, for physician and total services.

Regarding hospitalization, the positive and significant coefficient of ADL indicates that those children whose conditions were more severe, regardless of diagnosis, were more likely to be hospitalized and to have longer stays ($b = 0.02$ $P < 0.001$ and 1.22 $P < 0.01$, respectively) ($P < 0.001$). Thus, need appears to influence likelihood and length of hospitalization. Race exerted an influence on initial access to inpatient care: Black children with chronic conditions, controlling for all other variables, were 13% less likely than white children to be hospitalized. Once admitted, however, the length of stay of black children was not significantly different from that of white children.

Overall, severity did not influence the volume of physician visits. Race, however, exerted an effect: Black children made about three fewer physician visits than white children over the course of a year.

Children with more severe disability were more likely to use physical therapy than those whose conditions were less severe ($P < 0.001$). No influence of socioeconomic factors on likelihood of physical therapy use was evident. In contrast, volume of use among those who saw a physical therapist at least once did not differ significantly by diagnosis or severity, but was positively related to family income; with a family income rise of $1,000, a disabled child made nearly one additional visit to a physical therapist ($P < 0.05$).

Neither severity nor socioeconomic factors influenced proportion or volume of mental health service use. The same was true for use of dentists. In both cases, diagnosis exerted the only significant influence on likelihood of use; among users of these services, there were no significant differences in volume of use by diagnoses, severity, or SES.

Total use of services was influenced by both severity and SES. Overall, children with more severe conditions, regardless of diagnosis, used more services than those whose conditions were less severe. Black children used approximately 50 fewer services than nonblack children, even when

TABLE 9. Regression of Use of Services by Chronically Ill and Disabled Children on Diagnosis, Severity, and Socioeconomic Status (Unstandardized Coefficients)

	Probability of Use[a]				Volume of Use					
	Hospital	Dentist	Physical Therapy	Mental Health	Hospital	Dentist	Physical Therapy	Mental Health	Physician	Total Services
CP[e]	−0.09	0.18[b]	0.44[c]	0.21[d]	0.31	0.70	−15.58	16.16	−4.44[b]	55.25[d]
Muscle[e]	−0.04	0.33[c]	0.38[c]	0.31[c]	−8.54	0.38	− 9.67	6.20	−1.09	44.34[b]
MH[e]	0.04	0.14	0.18[b]	0.32[c]	−8.14	0.44	−25.07	10.19	−1.63	35.50
ADL[f]	0.02[c]	−0.00	0.02[c]	0.00	1.22[d]	−0.08	0.85	−0.20	0.12	5.38[c]
Education[g]	−0.01	−0.01	−0.01	−0.00	−1.43	0.11	1.04	0.67	0.28	− 1.99
Income[h]	0.00	−0.00	0.00	−0.00	−0.11	−0.02	0.98[b]	0.03	0.01	− 1.29
Race[i]	−0.13[b]	−0.08	0.02	0.08	6.26	−1.27	−23.09	−9.08	−3.06[b]	−51.19[d]
R^2	0.07	0.09	0.29	0.10	0.16	0.08	0.10	0.06	0.07	0.15
n	369	369	369	369	124	225	168	134	369	369

Note: Sex of child, age of child (years), marital status (married/not married), mother's employment (employed/unemployed), and number of children in the household were controlled for in the analysis.

[a] Dummy variable: 1, service was used; 0, service not used.

[b] $P < 0.05$

[c] $P < 0.001$

[d] $P < 0.01$

[e] Diagnostic category coded as set of three dummy variables with cystic fibrosis as a reference group.

[f] Activities of daily living (ADL): Severity of disability, a six-item Likert scale that measures the extent to which the child gets help eating, dressing, washing, toileting, going up or down stairs, and going outside; scores range from 0 (no disability) to 18 (high disability).

[g] Mother's education in years.

[h] Family income in thousands of dollars.

[i] Dummy variable: 1, black; 0, white.

diagnosis, severity, and the remaining independent and control variables are taken into account (b = −51.19, $P < 0.01$).

Summary and Discussion

The use of health services by chronically ill or disabled children in this study has four outstanding features:

1. Use of hospital and outpatient care by these children was markedly greater than by children free of chronic conditions. With respect to both hospital days and use of outpatient services, the average chronically ill child exceeded 10-fold the average "normal" child. The major categories of practitioners they used disproportionately are physicians (particularly specialists), rehabilitation workers (especially occupational therapists and physical therapists), and school nurses. In contrast, the amount of dental care received by children with chronic conditions was, on the average, similar to that of other children. The use of nutritionists or dieticians was almost equally rare in the two groups. Although the amount of mental health and social services used by children with chronic conditions exceeded that used by "normal" children, its contribution to the overall difference between the two groups was relatively minor.[7]

2. Amount and type of outpatient care varied extensively across the four conditions. Hospital care, in contrast, was used by similar proportions and in similar amounts across diagnostic groups. The major disparity in outpatient care was between children with CF and children with the three remaining conditions (CP, MY and MH). Total outpatient services used by children with CF was, on the average, far lower than by children with other conditions; it was comprised almost exclusively of care from physicians, chiefly specialists, who were seen by CF patients more frequently than by other chronically ill or disabled children. The only nonphysician health care professional used extensively by children with CF (and in equal amount to that of children with other conditions) was the school nurse. It should be noted that most schools require that a school nurse dispense medications. This practice may account for the high frequency of visits to the school nurse.

3. Chronically ill or disabled children were far from uniform in their use of health care. The major share of health care used by the total sample in the year of the study is attributable to a small subset of children. All hospital care was accounted for by one third of the sample and three quarters of all outpatient care by one quarter of the sample.

4. Severity of functional impairment and socioeconomic factors, in particular, race, exerted independent effects on the likelihood and frequency of use of outpatient services. Severity of impairment was positively related as well to both the probability of hospitalization and the length of stay. While black children were less likely to be hospitalized than their white counterparts, once in the hospital, the lengths of stay of the two groups were comparable.

Although accurate calculations of expenditures associated with services used is beyond the scope of this study, we have made some order-of-magnitude estimates for hospital, physician, and dentist on the basis of national reports of medical expenditures.# Because national data on other services discussed in this paper are unavailable, physician visit expenditure was used as an estimate and the lower hourly wage of nonphysicians is assumed to be offset by the opposite trend in the average length of visits.

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[7] Support for the generalizability of findings from the Cleveland Study is provided by a comparison of utilization data from our randomly selected control sample with data from the 1976 National Health Interview Survey (NHIS).[8] Because the age range of children is not identical (3–16 years in our study compared with 0–16 years in the NHIS), some differences can be expected. The NHIS reports that 5.1% of children were hospitalized in 1976, while our control sample estimate is 6.1%. Mean number of hospital days reported for children with one hospital stay or more is 6.5 nationwide and 6.2 for the Cleveland random sample. The NHIS report that 88.4 of the children saw a physician in 1976 and that the average number of visits was 4.1. The experience of the Cleveland random sample was similar, with 88.4 reporting a physician visit in 1976 and an average number of visits of 3.3. Finally, the percent seeing a dentist in 1976 is 61.4 in the national sample and 69.3 in the Cleveland sample.

By multiplying the estimated average expenditures per unit of various services by utilization means generated in this study and summing these products, we estimate that the total yearly expenditure for health used by an "average" chronically ill or disabled child was roughly 10 times greater than that of the average child in the general Cleveland population ($3,200 vs. $300 per child per year in 1978 dollars). The magnitude of this difference varied across diagnoses, from six fold for the average CF patient to 12-fold for the average child with cerebral palsy.¶

Hospitalization accounted for 50% or more of the total expenditure for the disabled and chronically ill sample, but for only 39% of the total expenditure for the control sample. In contrast, estimated expenditures associated with psychologic, counseling, and social work services accounted for about 5% of the total expenditures for the average chronically ill or disabled child.

The observed distribution pattern of expenditures across the various categories of health services might be attributable in part to reimbursement rules of private as well as public insurance programs. Counseling and psychologic services are much less likely than hospitalization to be covered by these programs. Although rehabilitation services are often excluded from insurance coverage as well, they are provided to children with disabilities primarily at school, as our data indicate. (During the year of the study, 88% of the children in the chronically ill or disabled sample who used speech therapy, 56% of those using physical therapy and 70% of those using occupational therapy, received these services in school. About 90% of the parents whose children received these services said they paid nothing out of pocket for these services.) The cost-effectiveness of this distribution of resources and their appropriateness for children in various diagnostic categories are important policy issues on which few data are available. More research is needed on the contribution of specific surgical, rehabilitative, or other services to the functioning of chronically ill or disabled children.

Although previous reports have demonstrated that marked variations in the use of health services characterize the general child population,[17–19] little has been known previously about such heterogeneity within the population of chronically ill or disabled children. In the general population of children, those classified as heavy users in one year were found to be likely to remain in this class in subsequent years.[19] Whether or not such continuity also is reached among children with chronic illness or disability cannot be acertained in

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# The estimated expenditure per hospital day in 1978 for children approximately 0–17 years of age is $294, assuming an average per-child expenditure of $101.75[13] and an average per-child hospital stay of 0.346 days.[16] The estimated expenditure per physician visit for children is $18.31, assuming an annual expenditure per child of $75.06[13] and an average of 4.1 visits per child.[6] The estimated expenditure per dentist visit in 1978 for children is $25.00, assuming an average per-child expenditure of $40.01[13] and an average number of visits of 1.6.[16]

¶ The figures for 1978 per capita expenditure are for children 0–18 years of age, whereas those for utilization rates are for children 0–16 years of age. We therefore estimate that the per-unit figures are for children 0–17 years of age. The estimated excess expenditure per child with these chronic conditions ($2,900) is higher than another recent $1,000 estimate for children with limitation of activity due to chronic conditions.[16] This discrepancy may result from the fact that the national data upon which the lower figures are based are heavily weighted by children with less serious conditions, such as asthma. The hospital-based nature of the samples used in the present analysis could also contribute to the difference in estimates.

this study, because data are available only for a single year.

The data do provide some clues, in that diagnostic category emerged as an important factor. To the extent that there are differences across conditions in the degree to which some services (e.g., physical therapists) are clinically indicated, we might find consistency of use over time associated with diagnosis.

Other factors suggest, however, that in this population heavy use in one year might not be followed by heavy use in subsequent years. Surgical procedures to remedy congenital malformation require extensive use of hospital and follow-up care during a limited period. Therefore, heavy use of services associated with such procedures within one year would not be representative of a child's use of health care over a longer period. Further, the natural history of some conditions may dictate a particular course of interventions requiring varying amounts of services over time.

The actual relationship between need (as indexed by severity) and use of hospital and outpatient services might be even greater than our estimates show. Because severity was measured at the conclusion of the year for which data on utilization were collected, the relationship observed may have been attenuated by the presumed beneficial effect of utilization on health status. This may also explain the lack of a significant relationship between functional impairment and some specific types of services, such as physician use. Longitudinal studies to clarify the relationship between severity and utilization are clearly needed.

Our data on income support the prevailing notion that there is a wide variation in the amount and pattern of financial support available for children in different economic circumstances, and that this diversity influences use of services. In our sample of children with chronic conditions, all but 4.6% reported having private insurance, Medicaid, and/or Crippled Childrens Services coverage. We do not have data on the comprehensiveness of that coverage, which may have influenced use. In general, income did not emerge as a barrier to access. With regard to physical therapy use, however, those with higher income had more visits. Additional analysis showed that both the direction and strength of the relationship between income and use of physical therapy services varied by diagnosis. The lack of influence of mother's education on utilization is noteworthy in that this variable is considered an important indicator or use of services by the general pediatric population.

Interpretation of the observed differences across diagnoses is limited by the close tie between diagnosis and source of care in this study. With minor exceptions, children with different conditions were enrolled in specialty clinics organized and staffed differently. The striking differences in use of outpatient services between children with CF and children with other conditions, for example, may well have resulted from a combination of condition-specific needs, variation in clinic staffing and orientation toward comprehensiveness of care, and numerous historical factors. Some of the differences in frequency of use may be due to variation in the number of physician-initiated follow-up visits. Clearly, more research is needed. Longitudinal studies of use of services over several years, in multiple settings and for a variety of diseases, are needed.

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ALBERT EINSTEIN COLLEGE OF MEDICINE
OF YESHIVA UNIVERSITY
1300 MORRIS PARK AVENUE, BRONX, N.Y. 10461 • CABLE: EINCOLLMED, N.Y.

DEPARTMENT OF PEDIATRICS
Pediatric Ambulatory Care Division

Mailing Address
Bronx Municipal Hospital Center
Jacobi Hospital
Pelham Pkwy. & Eastchester Rd.
Bronx, New York 10461

April 9, 1985

Select Committee on Children,
Youth and Families
Room 385
House Annex II
Washington, D.C. 20515

Enclosed are some articles related to the effects of chronic illness on families. I hope they will be useful to you and the members of the Select Committee.

Please let me know if I can be of further assistance.

Sincerely,

Ruth Stein

Ruth Stein, M.D.
Director, Division of
Pediatric Ambulatory Care

RS/lr
encls.

Growing Up With a Physical Difference

Ruth Stein

Although childhood is supposed to be a time of well-being, many of our nation's children have significant, continuing physical health problems that make them distinctly different from their healthy peers. As a result, these children face special challenges as they grow up. This article explores the implications of growing up with a physical difference by focusing on four issues: Why are physical differences important? To what extent can we appropriately generalize across diagnoses? What are the developmental and familial consequences of chronic health impairments? What can be done to improve the situation? The author discusses developments contributing to a heightened concern for these children and reviews objective data underlying a noncategorial approach to childhood chronic illness. Attention is paid to the consequences of a chronic illness for the child, the family, and the school—and how health care providers can minimize the negative consequences. As a whole, the evidence indicates that chronically ill children and their families can be effectively helped within the context of care normally provided.

My topic is growing up with a difference—specifically with a physical difference. Childhood is supposed to be a time of well-being or at worst a period of limited transient illness. Nevertheless, there are literally thousands of our nation's children who have significant ongoing physical health problems that make them distinctly different from their healthy peers. In fact, our best current estimates are that somewhere over 10% of our nation's children have some form of chronic problem affecting their physical health; some estimates place the number closer to 20% (Haggerty, Roghmann & Pless, 1975; Pless & Pinkerton, 1975; Starfield & Pless, 1980; Travis, 1976) and there may be twice as many among the poor (Egbuonu & Starfield, 1982; Gliedman & Roth, 1980). Of these only a small fraction, perhaps 2 or 3% of children, actually have limitations in their normal range of daily activities. Many more have periodic exacerbations and remissions, and virtually all require some special health services. All these children with ongoing health conditions face important issues in growing up. It is these issues, and our role in helping with them, that I will address. By increasing our awareness of the central concerns, I believe that we may improve our ability to understand and assist both healthy and physically impaired children and their families.

What do I mean by a physical difference? For this article, I will ignore the large number of personal characteristics that define the uniqueness of each individual and that make an individual stand out; instead I will concentrate on physical deviance associated with a health problem or ongoing conditions that separates a child from his or her healthy age-mates. One useful definition is taken from Pless and Pinkerton (1975), who define a chronic health condition as one that lasts 3 months or more or requires a period of hospitalization of at least one month duration. This definition includes both visible and nonvisible physical differences—a point worth noting now and one that I will later discuss at length.

What are the characteristics of such physical conditions? These health problems have many common features; all are of long duration, many will last for the child's whole life, and some will result in shortened life expectancy. Often they are associated with the need for specialized services and in some instances for painful treatments and hospitalizations. They are characterized by the fact that they require our care, but most often we cannot cure them. Such conditions inherently threaten a child's potential for normal physical and emotional growth and development. In addition, they may have severe potential for disrupting family life. Further, in contrast to many types of acute illness that can be managed with only minimal knowledge about the individual patient or his family, the care of

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Ruth Stein, MD, is at the Department of Pediatrics, Albert Einstein School of Medicine, and the Division of Ambulatory Care, Bronx Municipal Hospital Center, Bronx, New York 10461.

children with ongoing physical illness requires extensive knowledge about the patient's family life. Gliedman and Roth (1980) note that "unless the child is to be permanently sequestered in a hospital ward, management of a chronic disorder never takes place in a vacuum; it must be carried out within the context of ongoing family life, where management of the child's biological condition is only one of many pressing demands...." (p. 240). This requires us to keep a focus on the whole child and his family and may run counter to some current trends toward increasing subspecialization of services.

There are several major issues which need to be addressed:

1. Why are physical differences in the growing child especially important now?
2. Is there any basis for talking about children with physical problems as a group or should each condition be considered separately? To what extent can we generalize about these differences?
3. Should we be concerned about children growing up with physical differences? What do we know about the consequences of chronic health impairments for children and their families?
4. What can we, as individuals concerned with the care of children's health, do to improve the situation?

Let us consider each of these areas in turn.

First, why should we be concerned now with physical problems of children? Although there is little evidence of an overall increase in the number of children with ongoing physical problems in the population, these children do consume a larger share of our time as health professionals. This is a result partly of our success in immunization programs and antibiotic therapy, which have radically reduced the morbidity and mortality of the whole pediatric population, and partly due to tremendous advances in disease-specific therapies that allow children with a wide variety of problems to survive longer into adolescence and adulthood. Therefore, many more health professionals will have contacts with children who have chronic physical disorders, and although each of us may see only a few in any one disease category, our total number of interactions with children with ongoing health problems is sizable and likely to continue to grow. Moreover, children with physical differences are no longer hidden in institutions or at home; increasingly they are being mainstreamed in our society, so that the daily issues of managing in the community are of heightened concern.

Another reason to pay attention to the issue of physical conditions is that, as biomedical technology increases, it may outstrip both our ability and willingness to pay for the full range of services that we know how to provide. Perhaps even more importantly, this technical progress might surpass our ability to deal with the related personal, social, and ethical issues entailed in giving care to these children. We are all aware of escalating health care expenses, of the lack of psychosocial supports and services aimed at improving adjustment and adaptation in daily life, and of difficult ethical issues in care. As we concern ourselves with questions about the quality, as well as the quantity, of life we preserve, we realize that, in order to make intelligent assessments, we must take stock of what we know about living with a physical impairment. These issues are particularly critical for the growth of children faced with life-long health problems.

But exactly who are these children? Many professionals might look for a diagnostic grouping or classification. After all, health professionals typically group children by diagnoses and emphasize that each disease is unique, has its own problems, and is much more devastating than any other. What is the evidence that children with ongoing health conditions can be considered as a group unto themselves?

Medical training, practice, and research are traditionally organized around body systems and disease categories. This method of categorization is based on the assumption that clinical diagnoses provide information important for patient care and that children with a particular diagnostic label exhibit great similarities. A disease-specific approach has been the cornerstone of research on both biomedical and psychosocial aspects of illness to the point that there is great reluctance to make generalizations or to study issues across diseases. Much of the original research describing the effects of chronic disorders grew out of observations made by subspecialists dealing with a large number of patients with a particular diagnosis and led to the descriptions of "characteristic profiles" of patients with a given condition (e.g., asthma, hemophilia, cystic fibrosis, meningomyelocele).

Disease-specific research focused on biomedical cures for individual disease entities must be sustained. However, is it equally desirable to use diagnostic labels when examining the broader issues of the effects of illness on the child and family unit, particularly the issues in growing up? Jessop and I have argued (Stein & Jessop, 1982a) that it may now be useful to adopt a new framework in viewing chronic conditions in childhood, because as children with physical health problems survive into adolescence and adulthood, they face problems of adjustment for which a great many variables other than diagnosis have importance. Our understanding of these variables is often hampered by the assumed supremacy or preeminence of the diagnosis as the single most important factor.

In a wonderful monograph entitled *Chronic Childhood Disorder*, Pless and Pinkerton (1975) review a large number of studies of adjustment of children with different individual diagnoses. From these studies of separate health conditions, they show that all the groups of children and their families face similar problems. They come to the conclusion that many physical disorders have identical consequences in terms of development and adjustment and that issues in rearing a child with a physical health problem are parallel, regardless of the nature of the child's condition. Based on the evidence, they argue that from the point of view of the child and family the specific health problem is not the central issue in growing up; instead, the very existence of a health condition causes families to share a number of problems in raising the child, whether the condition is diabetes, asthma, or kidney disease. They propose a generic or noncategorical approach, one that groups children with chronic physical disorders across diagnostic boundaries.

This perspective is counterintuitive for many in the health field, and especially difficult for physicians, who have been trained to focus on differences among health conditions rather than on their commonalities. From the pediatrician's framework it may be extremely hard to find much in common among distinct health conditions and easy to find much that differs among them. To those in other disciplines and to the lay community, it may be no surprise that there are many common themes among individual families of a child with an ongoing health problem. Many who work with children with different diagnoses know this well from clinical experience in clinics, inpatient units, playrooms, and classrooms.

In work that Jessop and I have done recently at Einstein, we have examined children with different chronic diagnoses and looked at a large number of social and psychological areas to test Pless' and Pinkerton's theses and to see if in fact there are measurable differences among groups of children and their families that are determined by the diagnostic categories to which the child belongs (Stein & Jessop, 1982b). Our hypothesis was that there would be more differences among children within any one individual diagnostic grouping than there would be *between* diagnostic categories. If this were true, it would provide an objective basis for a noncategorical or generic approach and would serve to underscore the view that children with diverse medical problems have great similarities in their life experiences. Moreover, it would allow us to group children with different physical health conditions as a single class.

The data that we used in these analyses were collected from mothers in home interviews at enrollement in the Pediatric Ambulatory Care Treatment Study (PACTS), a large-scale randomized trial of two modes of service delivery to chronically ill children at the Albert Einstein College of Medicine-Bronx Municipal Hospital Center. The sample included 209 children less than 11 years old with chronic conditions who met eligibility requirements for our PACT Study. The definition of chronic illness used was the same as the one I mentioned earlier.

The 209 children had over 100 different conditions. They included sickle cell anemia, asthma, diabetes, leukemia, juvenile rheumatoid arthritis, and congenital conditions such as meningomyelocele and biliary atresia. About one-half of the children have more than one condition—in some cases as many as nine. The families were for the most part poor urban families, largely from minority groups. We selected all the diagnostic groups in our study which had 10 or more subjects, excluding cases that had more than one of the conditions. There were four diagnoses with sufficient numbers: meningomyelocele/hydrocephalus, seizure disorder, hemoglobinopathies, and asthma. For each diagnostic group we determined the ranges, means or averages, and standard deviations. Using statistical tests (analyses of variance), we looked to see whether or not the four groups differ.

We examined a range of measures satisfying customary standards of reliability to see whether the variation *between* diagnostic groups is as large or larger on these measures than the variation *within* the groups. We found that while the diagnostic labels are indispensable in managing the physical and biomedical aspects of a child's condition, they just do not tell very much about many areas of concern in the lives of chronically ill children and their families. When we moved from the narrowly defined biomedical issues and measures of health care delivery to a broader view, the diagnosis gave little information about the status of the child and family.

Those who are concerned with a broad range of health care issues may find a noncategorical approach most helpful because it allows us to look at many small clusters of children as a group. This perspective enlarges our opportunities to understand developmental and behavioral issues and to learn about growing up with a physical condition in children with a range of health problems. It also encourages us to work with community or population-based samples and to develop programs targeted to meet the needs of children with a range of differing conditions, rather than just one disease type. This approach also permits the individual practitioner, who sees only a small number of children with any given disease, to use experiences gained from the care of children with cystic fibrosis or kidney disease to care for a child with diabetes.

Having suggested that we are justified in thinking about all children with a physical health condition as a group, we face another important question: Are there any features of the illness or condition that differentiate some of these children from others and that indicate who is at more or less risk for the negative social and psychological consequences of illness? In a second set of analyses we examined whether certain features or dimensions of conditions might be helpful to clinicians in thinking about the consequences of the child's disorder. We used information from a Clinicians' Overall Burden Index (Stein & Jessop, 1982a) that was rated by each child's physician and that defined 17 dimensions of illness. We found (Stein & Jessop, 1983) that the consequences are more negative where there is poor functioning and where the condition is not visible. This finding had not previously been emphasized, except perhaps in a few references that suggest that marginal illness may have a disproportionately more serious effect on psychosocial adjustment than those that are clearly debilitating (Barker, Wright, Myerson & Gonick, 1953; McAnarney, Pless, Satterwhite, & Friedman, 1974).

How can we explain these results? These two seemingly opposing findings and the importance of needing to watch for changes can perhaps be understood within the framework of the concept of uncertainty. Lack of visible difference between a chronically impaired child and well peers may make it more difficult to recognize that the child has a chronic condition. If the physical difference is not obvious to the outside world, a child may need to be "sicker" before the condition can be fully acknowledged. This may produce an uncertainty that is psychologically unsettling and associated (a) with more negative psychological consequences for the mother and (b) with greater perceived impact of the illness of the family. The unpredictability may lead to insecurity (Wright, 1960), something our analyses suggest is so among families of children with chronic physical illness.

The role of uncertainty in affecting the way patients' experience illness may not fit with the ideas of physicians, who are inclined to think that things are going well if the child is functioning and bears no visible signs of physical difference. "Common sense" professional notions suggest that a child who appears well part of the time is better off than someone who is always sick, something that does not appear to be true. Understanding this finding is essential in order to understand the viewpoint of the patient and family. This observation also underscores the importance of including in our discussion of physical differences those children whose physical health is impaired, even if it does not show easily to the outside world.

To summarize, the evidence suggests (a) that we can and should think about children with a chronic physical difference as a group and (b) that there are only a few dimensions of the physical conditions that may be associated with differential risks for adjustment.

The next issue that concerns us is how physical differences affect development and why we should be especially concerned with the developmental process in this special cluster of children. The following paragraph focuses on some of the domains of a child and family's life that may be affected by the child's condition and on what we can do to minimize this effect.

Daeschner and Cerreto (in press) have written that children with an ongoing physical problem are "...constantly part ill and part well—but never free of a problem that sets them apart. Their families, their social interaction, their educations and their daily routines are different from those of their peers." (p. 29). And Linda Hexter (1980), herself a mother of a child with a serious chronic condition, writes that "...birth and/or diagnosis of a chronically ill child is one of the most severe stresses that a family can sustain, because it involves not only the sudden shock and grief experienced when the child is diagnosed but also years of multiple traumatic events, constant medical treatment, and continual worry and anxiety" (p. 143).

An important area of work pertains to the consequences of childhood illness for family life. The bulk of the evidence seems to suggest that ongoing physical illness may disrupt the entire fabric of a family, especially during the crisis phase. Diagnosis of a major health problem in a child is a severe stressor causing strains in a variety of areas—emotional, physical, financial, and social. The initial emotional response may be a mixture of fear, anxiety, anger, depression and guilt. Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) suggest there is an initial shock, then denial, sadness, and anger, and only after time the reestablishment of equilibrium and the capacity of the family to reorganize and get on with the tasks of living. Individual members may travel through this sequence at different paces, and exacerbations of the condition can lead to renewed confrontations.

Many parents, if not most, feel some sense of personal failure or question their own adequacy as parents. Virtually every family wonders what they might have done differently to prevent the child's condition and many common themes run through their fantasies about possible causes. When the child reaches critical developmental stages, such as when toddlers begin to demonstrate independent motor skills, when children enter school, or when adolescence begins, parents are confronted by the ways in which their own child's current function, special care needs, or future potential may differ from peers. Some families handle these worries with little mutual support, as each parent reacts to his or her own emotional needs using coping mechanisms that may be divergent from the other parent's.

Family members may be affected by both the illness and by the demands placed on them by the health care system with respect to the care of the child's physical problem. Expectations for treatments and home management may become very taxing. There may be a change in reality in the physical aspects of daily living—in trips to health facilities, in special diets or medical procedures, perhaps the child's sleep pattern or ability to develop independence in dressing, toileting or learning. This often leads to a realignment of family members with the mother in most families bearing the brunt of day-to-day responsibilities. The mother spends the bulk of her time with the impaired child; the siblings manage relatively more independently or by spending more time with the father or another adult.

For the child and family, ordinary events of life may have greater than normal impact. A move to a new home away from familiar sources of care and community supports may be very traumatic; the potential disruption may be so severe, in fact, that a family forgoes the move. Even commonplace events, such as the birth of a sibling or a family vacation, may pose special problems. Adaptation to these ordinary occurrences cannot be taken for granted but may require a good deal of planning and anticipation.

Then there are the costs. Most families are determined to get the best care they can for the child; often they will expend great financial, as well as emotional, resources in the hope of finding a cure. The financial realities, even for those who can find care nearby, are enormous. Insurance policies are capricious; eligibility for public support is often inconsistent; and public monies for supportive or preventive services are meager. There are also the hidden costs; lost opportunities, lost work time, lost chances to advance in one's career or to go back to school. Opportunity to change jobs may be missed because a parent fears the loss of insurance coverage. Lack of energy to be a resourceful bargain hunter or homemaker, and the costs associated with the desire to find ways of trying to "make it up" to the sick child, may produce secondary economic burdens. There may be no time or money for vacations or recreation.

Another affected area is that of personal strain created by fatigue and intrafamilial tension. This is accentuated by, and contributes to, social isolation. Parents may be unable to find a babysitter and get away even for a few hours. It is often difficult to maintain friendships, and the constant worry and fatigue may detract from being "good company." All these lead to an isolation that may be coupled with resentment of the need to be dependent on the few remaining family, neighbors, and friends for favors without the ability to reciprocate.

It is important to note that social supports—that is, the presence of a helpful social network—appear to be a major predictor of successful coping with the care of a child with a physical disorder. Therefore, it is extremely important to encourage retention of the family's social network. Yet, we find a very common, almost universal, response to physical illness is withdrawal. People often pull away because they feel uncomfortable about how to act, what to do or say.

Still another set of concerns is in the area of needed services. Although, the presence of a physical problem may assure contact with health professionals, a growing number of studies indicate that this contact may not guarantee that the child receives a full range of basic services, even those as basic as immunizations and screenings, help with long-range planning, and coordination of care. Services that are rendered have been referred to as "patchwork care" (Daeschner & Cerreto, in press), and there is generally no reimbursement for primary care, coordination, advocacy, or support services.

School is an important area for the growing child, but here too there are problems. Despite recent efforts, such as PL 94-142, many children continue to receive inadequate schooling or are placed in unnecessarily restrictive environments. A school principal told me recently that in her school children with handicaps were no longer going to be mainstreamed, because "they had no place to go during gym period." This may indeed be a problem for the school, but return to special class placement means isolation from healthy peers, often inadequate intellectual challenge, and consequent eductional disadvantage. In school, even in regular classes, teachers may have lower expectation for the health-impaired child. Also, special services, such as physical therapy during school hours, decrease the actual amount of classroom time and peer contact for children with physical conditions. Serious physical problems may also result in a suspension of activities that are important to long-term success. This may occur because of periods of restricted activity, absences from school, hospitalization, or even preoccupation with the possibility that the child might not survive.

In school and at home there is often uncertainty about how to treat the child and a tendency to spoil, baby, or overprotect. This deprives the child of important lessons in living and may result in significant social morbidity later on. Children who are isolated and not offered the normal range of give and take with peers do not master age-appropriate social skills or mature socially at the same pace as their agemates. Inclusion in household chores, normal sibling squabbles, and neighborhood and after school activities are important growing experiences whenever they can be made available. These opportunities enhance social feedback and ultimately a sense of self worth. However many parents and professionals discourage these activities because of misguided thoughts that they can protect the child from being "hurt" in the sometimes cruel world.

As I suggested earlier, in the social sphere there are major differences for children who have visible as opposed to invisible conditions. In the presence of invisible conditions, society presumes that everything is normal. This creates confusion, ambiguity, and anxiety if the child is impaired in his or her ability to take part in a full range of activities. How often have you heard someone say, "but I don't understand, she looks fine" or "I didn't know he was sick because he seemed okay?" For the child with a visible physical difference, the presumption is one of incompetence or lack of ability. This may be equally inappropriate and creates another kind of anxiety and uncertainty—the need for the child to prove that he or she is capable. Take notice the next time you hear someone speaking in overly simplified terms to a stunted adolescent or to a child in a wheelchair or shouting at the blind child. These actions are based on the misassumption that the stunted adolescent is a younger child, or the wheel chair bound person is retarded, or the blind person is more globally impaired and cannot hear.

Richardson (1963) notes that, in general, our society is less at ease with those with a handicap and is put off at the first contact. Only after time does the social interaction break through the initial barrier; still, relationships often remain at a formal level. One specific task that a child who is physically different must master is how to break through and make others comfortable enough to allow for social interchange. Negative stereotyping attitudes are learned early and result in barriers to interpersonal relationships, discrimination, and systematic devaluation of the physically impaired (Ireys, 1981; Gliedman & Roth, 1980).

In a moving chapter of *Journey* written by parents of a child with a chronic physical condition, Massie writes that "People were always afraid of us. I could sense this, it is as though they felt we had been touched with a curse and that too close contact might contaminate them or give them a glimpse of an unpleasant reality they wanted to avoid having to face." (Massie & Massie, 1975, p. 167–168).

To the extent that there is a heightened awareness of physical differences in the social world at large, a negative attitude may spill over to siblings. While siblings of chronically ill children often get less attention from their parents than other children do, they may be quite conspicuous in their social world as the brother or sister of the child with X or Y condition. Just think the next time you are in McDonald's and see a physically different child about your own increased tendency to notice the entire family grouping. Having a physically different brother or sister changes many relationships for the well child—his relationships with his parents, sibs, and the outside world. For siblings there may also be extra family responsibilities and the responsibility of being an intermediary between the outside world and their physically disadvantaged siblings. All the normal problems of sibling rivalry and conflicts are heightened and exaggerated. Additionally, brother and sisters are often excluded from information about the nature and implication of the condition, because it is falsely assumed that they can or should be "protected."

Undoubtedly, there are some who will see these statements as a gross oversimplification. Focusing on common themes is not intended to obscure individual differences, but rather to stress that differences, where they occur, are often due as much to the specific family or child as to the specific disease. It is all too easy to attribute them to a single cause—the child's particular physical condition. A colleague who recently spoke to a group of parents of young children with significant developmental delay illustrated this point. She said that the parents were seeking advice about separation problems, temper tantrums, and sleeping disorders. Many were totally unaware that any of these problems occurred in "normal" children. They attributed them all, in a kind of magical thinking, to the child's developmental difference. To illustrate this further, let me tell you about Malcolm, an unusually articulate 22-year-old with Down's Syndrome. In preparing this material, I asked him if he could help me by telling me what he remembers about growing up different. He quickly responded that what he remembers most is being "bad" and being "scared," especially of thunder and lightning at night. He reminds us that these special children are more like other children then they are unlike them.

This then is a critical concept in growing up with a physical difference; physical disorders occur in developing children, in a dynamic and ever-changing context. Indeed, focusing on physical differences in children forces us to consider developmental issues. The problems faced by an ill child and his family very much depend on complex interactions between the child's physical condition and his development. For each child and family, the situation is unique. Some health problems, such as asthma, can occur through the course of childhood, while others occur at particular ages and may cause more specific disruption of development. For example, the birth of a child with a congenital disorder causes stress during the important and critical period of bonding, while a serious change in health of an adolescent can interfere with the development of adult autonomy. Many issues that span childhood have different manifestations and meaning in each stage of development. Hospitalization with its attendant separation from the family has different meanings for the infant, the toddler, the school-aged child, or the adolescent.

One controversial issue is whether development of a child with a serious life-long physical condition can be expected to follow the development of healthy children. Gliedman and Roth (1980) suggest that it may not be fair to use our concepts of normal child development and apply them to children with special physical problems and handicapping conditions because their life experiences may differ too greatly from those of their healthy peers. Whether or not we agree, it is clear that several types of development are superimposed on one another and occur simultaneously. There is the child's individual development, the changing family as it evolves in its own life cycle, the changing course of the physical condition, and the unfolding adaptation to it. The issues faced by the child and the family depend on and must be dealt with in the context of these complex interactions.

It is not uncommon to ask what the child's development would be like without the influence of the existing physical condition. The Reverend Robert Massie, Jr. (in press), a hemophiliac, recently wrote that it would be impossible to describe what he would be like without the presence of his hemophilia. Rhetorically he asks who Helen Keller would have been had she been a sighted and hearing person? Since we cannot answer such questions, we must look to comparative evidence, which suggests that children with chronic physical disorder are at special risk and face problems of adjustment.

Studies suggest that physical illness in childhood is associated with significant risk of psychological sequelae. There is, however, controversy about the subgroups at risk and the extent of risk. Large scale epidemiologic studies show an increased incidence of psychological problems among children with chronic conditions and suggest that the severity of the child's illness and his functional limitations are associated with greater risk for psychological maladjustment.

Our own work suggests that, among children with chronic physical health conditions, those who have more absences and poor functional status have poorer adjustment, but that these relationships may differ within subgroups of the population and are strongest among those with the fewest buffers and least strong among those who have significant family support (Stein & Jessop, in press-a).

Children with chronic conditions not only exhibit twice the rates of mental disturbance of healthy children on a variety of psychiatric measures, but studies in the United States and

Great Britain suggest a higher incidence of behavior, learning, social, and school problems (Douglas, 1975; Pless & Roghman, 1971).

According to Klein and Simmons (1979) and Drotar and Bush (1982), an important variable in adjustment is the child's subjective definition of the disease's severity and perception of the parents. This supports the notion that the family's definition of the severity rather than that of the physician is a powerful predictor of outcome.

A few very recent studies suggest lower levels of psychological disturbance than earlier case reports had indicated, but all continue to support the notion that there are increased psychosocial problems in the population of children who are physically different. This is a real problem because many families have great difficulty in handling secondary emotional symptoms and in accepting the need for help in this sphere; they often have little time, energy, and money to devote to these areas. Also many of our mental health systems are poorly equipped to deal with individuals with serious physical health problems.

One thing is clear; even very serious and debilitating illness does not preclude successful adaptation by the child and family and positive mental health outcomes. The challenge is to learn how to make successful adaptation and adjustment even more common.

I have discussed a number of potentially serious consequences of childhood physical differences. From this discussion, questions must arise for us all: How can we help? Is there anything we can do to minimize the effects of growing up with a physical difference?

Outcomes of physical conditions in the growing child are influenced by a number of factors: characteristics of the child, the disease, the family, and the nature of interventions. Physically impaired pesons, irrespective of their age, must retain their integrity as human beings and be given the opportunity to participate in their families and in society as completely as their circumstances permit. The goals of management are to help the family and child adjust to the condition, to maximize the health and potential of the child—to confine the effects of the illness. We can buttress self concepts, focus on assets rather than deficits, enhance coping strategies, and hopefully thereby minimize many handicaps and their secondary sequelae.

Until recently, our sense that we could make a difference derived from clinical impression more than from objective evidence. Many of us were convinced by this alone. But at Einstein we have just completed a clinical, prospective, randomized experiment in which we provided comprehensive care through a home care team to children with chronic physical illness using an integrated biomedical and psychosocial approach.[*] The comprehensive home care program did have significant benefits in improving the family's satisfaction and child's psychological adjustment, as well as a more rapid decrease in maternal psychological symptoms (Stein & Jessop, in press-b). This is one of a few new pieces of evidence that we can and should continue our efforts to improve the lot of this large group of children who grow up with a physical difference. Moreover, we can do so within the context of the care that we normally provide. There are many ways to help, by being available and supportive, by anticipating, and by advocating for the needs of children with physical health problems.

As Reverend Robert Massie, Jr. (in press), writes, "chronic illness is a constant and sometimes overwhelming companion, a shadow both inseparable and eternal....(that) creates a tremendous need in the patient—child or adult—for a group of supportive and caring human beings to show by their words and actions that they will stay with the patient—through the physical and emotional roller-coaster of disease." He continues "...the greatest burden for a chronically ill child is not the pain, the anguish, or the disappointment, but the wall of emotional isolation with which we have encircled that child because of our own fears. We must look inside ourselves, face those fears, and despite them, reach out. Only the powers of a warm heart can alleviate the deep chill of a child's constant shadow." To those who care for children and their health, let me suggest that we take on this challenge.

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[*] *Editors' note: See Dr. Stein's description of the Pediatric Home Care Program in this issue.*

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Does Pediatric Home Care Make a Difference for Children with Chronic Illness? Findings from the Pediatric Ambulatory Care Treatment Study

Ruth E. K. Stein, MD, and Dorothy Jones Jessop, PhD

From the Pediatric Ambulatory Division, Albert Einstein College of Medicine, and Bronx Municipal Hospital Center, Bronx, New York

ABSTRACT. The ongoing care needed by children with chronic physical illness is a topic of national concern. The Pediatric Ambulatory Care Treatment Study (PACTS) is a classic pretest-posttest randomized experiment designed to evaluate a Pediatric Home Care (PHC) program in which an interdisciplinary team provides comprehensive primary health care, support, coordination, patient advocacy, and education to chronically ill children and their families. Home interviews were conducted by an independent research team with the 219 families at enrollment, 6 months, and 1 year; 80% completed all three interviews. Analyses indicate that pediatric home care is effective in improving the satisfaction of the family with care, in improving the child's psychological adjustment, and in lessening the psychiatric symptoms of the mother. The functional status of the children was equally well maintained in both groups, and there was no significant difference in the impact of the illness on the family between the two groups. There are indications that there may be a dose-related effect with respect to the child's psychological adjustment with those in the program for the longest period of time showing the greatest benefit. Such a home care program can be an effective intervention for minimizing the social and psychological consequences of chronic illness. *Pediatrics* 1984;73:845-853; *home care, chronic illness, comprehensive care, psychological adjustment, ambulatory care.*

Between 5% and 20% of American children have a chronic physical disorder.[1] The decline of acute infectious diseases and improvements in treatment of chronic disease have increased the longevity of children with chronic physical illness, and thus an increasing proportion of the care of children is devoted to chronic conditions. The current trend toward regionalization of care in high technology and other disease-specific tertiary services is based on the presumption that each condition requires unique specialized care for improved biomedical outcomes. However, some have expressed concern about this trend and have suggested that the effects of the illness on the growing child and his family cross diagnostic boundaries.[2-4] Although there has been significant biomedical research geared to prevention, treatment, and cure of specific conditions, there has been little research aimed at ameliorating the secondary psychological and social consequences of chronic childhood illnesses and understanding the psychological and social effects of alternate forms of health care delivery.

In 1970, a Pediatric Home Care (PHC) unit was established at the Albert Einstein College of Medicine-Bronx Municipal Hospital Center which provides comprehensive and integrated medical, psychological, and social services for a wide range of children with chronic illness. This program was conceptualized as an ambulatory special care unit. The services were based on the assumption that care must be organized to address issues of concern to families of children with chronic conditions and that these issues cross disease categories. Although the program is oriented to the health of the child, it focuses on the whole family and its needs. It seeks to foster patient independence and to maximize rehabilitation and adjustment. The care is delivered using an integrated biomedical and psychosocial approach. It involves the family actively in taking responsibility for increasing aspects of management and informed decision making with the health care

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Reprint requests to (R.E.K.S.) Pediatric Ambulatory Care Division, Albert Einstein College of Medicine, 1300 Morris Park Ave, Bronx, NY 10461.
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professionals. The services of the Pediatric Home Care (PHC) program include: monitoring the patient, delivering direct services, teaching therapeutic programs to the family and patient, coordinating services, patient advocacy, health education, and support. An interdisciplinary PHC team provides care. The core team for each patient consists of a generalist pediatrician, a pediatric nurse practitioner, and the patient's family. A social worker, consultant psychiatrist, and physical therapist are also available; the resident or referring doctor and the subspecialists involved with the child are included as appropriate in an individual case. Services are provided in the patient's home as needed, as well as in the traditional locations of the clinic, the inpatient units, and the PHC office. Home visits are conducted to teach the patient and family in the situation in which care will be given, as well as to evaluate medical, psychological, and social needs in the family context and household setting. (For more detail on PHC, see Stein.[6,7])

The Pediatric Ambulatory Care Treatment Study (PACTS) was funded in 1978 to evaluate the PHC program. It employs a pretest-posttest experimental design in which children with diagnostically heterogeneous chronic physical conditions were randomized either to the PHC program or to the sources of care traditionally offered in this hospital complex other than PHC (ie, standard care). The objectives of the study were to compare PHC with standard care on outcome indicators that might be sensitive to an intervention of the kind described above and might be common to children with a wide array of diagnoses. The purpose of this report is to present data that compare PHC with standard care on five major variables from that controlled trial: (1) satisfaction with care; (2) child's psychological adjustment; (3) mother's psychiatric symptoms; (4) impact of the illness on family; and (5) child's functional status.

Although some worried that such a program would have adverse effects on family members and on the child's health, we hypothesized that: (1) home care would be better than standard care with respect to satisfaction with care and child psychological adjustment; (2) the mother's psychiatric symptoms and the impact on family would be less in home care than in standard care; and (3) there would be no difference between home care and standard care in the functional status of children.

METHODS

Sample

The sample includes 219 children with diverse chronic conditions who met the eligibility criteria for the Pediatric Ambulatory Care Treatment Study and who were seen at a university-affiliated municipal teaching hospital during the period of June 1978 to January 1980. This facility serves children throughout the Bronx and offers a wide range of general and subspecialty services typical of a large municipal teaching hospital center. Criteria for inclusion in the study were the presence of a physical condition lasting three or more months or necessitating a period of continuous hospitalization of at least 1 month,[2] age below the 11th birthday, residence in the Bronx, need for care beyond that of a well child, and receipt of a portion of care through one of the affiliated hospitals of the Albert Einstein College of Medicine. Additionally, the child could not be moderately or severely retarded, had to be expected to live for the duration of the study year, and had to live in an English- or Spanish-speaking household. Only one child per family was enrolled in the study.

Although this is not a representative sample, it adds to our ability to generalize from the study to know the degree of success in enrolling subjects. Bilingual female lay interviewers recruited subjects from the inpatient service and subspecialty clinics. All children who came to the attention of the research staff, met the eligibility criteria for the study, and completed the enrollment procedures were included. Cooperation with the study was excellent. Children with a variety of conditions and varying levels of severity were entered into the study and randomized. During a 1½-year period, 381 children came to the attention of the research team before enrollment closed with 219 children. The greatest number (N = 92) of the remaining 162 children were excluded from the study because they did not meet one or more of the study's eligibility requirements. Thirty-nine additional children could not be traced and thus enrollment procedures could not be completed, and this group may include some passive refusals. There were 20 explicit refusals, four children were in another major study, and six children died before completion of the enrollment procedures. The limited information available for comparison of those included in the sample with those not included indicates no major difference in diagnosis.

The enrolled sample is heterogeneous with respect to diagnosis. The 219 children have more than 100 different conditions. These diagnoses include, but are not limited to: asthma (N = 76), seizure disorder (N = 26), hemoglobinopathy (N = 13), congenital heart disease (N = 7), malignancies (N = 6), diabetes mellitus (N = 5), and a variety of congenital anomalies such as meningomyelocele/hydrocephalus (N = 23) and biliary atresia (N =

TABLE 1. Pediatric Ambulatory Care Treatment Study Demographic Characteristics of Families for Total Sample at Time 1 (N ≥ 209)

Race/ethnicity	
Hispanic	60%
Black	27%
Other	13%
Marital status	
Married	40%
Divorced, separated, or widowed	33%
Single (never married)	27%
Family type	
Both parents	45%
Mother alone	39%
Mother with other adult	13%
Other	3%
Annual family income	
<$5,000	33%
≥$5,000 to <$9,000	37%
≥$9,000	30%
Source of income	
Public assistance	55%
No public assistance	45%
Mother employed	17%
Mother unemployed	83%
Other household member employed	55%
Other household member unemployed	45%
Level of education of mother	
<High school graduation	56%
≥High school graduation	44%

5). More than half of the children have multiple conditions, in some cases as many as nine. All required care at home beyond that of well children as measured by the Clinician's Overall Burden Index.[5]

The sociodemographic characteristics of the sample are shown in Table 1. The sample is entirely urban, predominantly poor, and composed largely of minority group members.

Study Procedures

The study was explained to the mothers by the lay interviewers and they were asked to sign an informed consent, approved by the Institutional Review Committee, agreeing to randomization to one of two types of follow-up care offered by the Department of Pediatrics, to three home interviews at 6-month intervals, and review of their child's medical records.

The research design called for stratification of the sample on two criteria that reflected the bases on which children had traditionally entered the PHC program: the resources of the family for dealing with the child's medical problems and the burden the child's condition would pose for any family. The first criterion, the Judged Ability to Cope, was obtained in a short structured interview with the mother. (In eight cases the respondent was a grandmother, aunt, foster mother, or other mother-substitute who was the primary caretaker.) The interview covered standard social and demographic information and measures of the social, psychological, and economic resources available to her in caring for the child. Internal consistency reliability for the total score is high ($\alpha = .76$, Cronbach[9]). The second criterion, the Clinician's Overall Burden Index, was obtained from the child's physician, and consisted of a standardized form, providing background medical information. The Clinician's Overall Burden Index included five dimensions of burden that the presence of an ill child places on a family beyond parenting a well child of the same age: medical/nursing tasks that parents need to perform; disruption in family routines entailed in caring for the patient; fixed deficits of the child requiring compensatory parental behavior; the added dependency of a child who cannot perform age-appropriate activities of daily living independently; and the psychological burden entailed in the child's prognosis. The items were weighted using previously derived weights and summed to obtain a total burden score for each child. Internal consistency reliability as measured by α (Cronbach[9]) is .70 for the total score. (See Stein and Jessop[5] for details on the development of this instrument.)

After determination of eligibility, the Judged Ability to Cope and the Clinician's Overall Burden Index were immediately hand scored, and the subject was assigned to a high, medium, or low category on each measure, and then randomized within a nine-cell stratification matrix. This was done using opaque sealed envelopes prepared in sets by a roll of a dice to determine the order of the first assignment within each set. The purpose of these procedures was to ensure that the two treatment groups were balanced with respect to these two areas thought to be relevant to outcomes. It was not the intent of the design to fill the nine cells. All scoring and randomization procedures were carried out by a member of the research staff independently of the clinicians, and the responsible clinician was notified of the group assignment. The PHC staff was notified as well each time a case was assigned to home care through randomization. Because of the nature of the intervention and likelihood of discovering group assignment during data collection, no attempt was made for patients, physicians, or interviewers to be blind to group assignment. However, interviewers were housed in a separate building and had no direct contact with clinicians in either PHC or standard care.

Study procedures dictated that all home care patients would receive at least a minimum package of care (an initial assessment, one home visit, and one monthly contact thereafter for at least 6 months), although obviously most patients would receive much more, based on their clinical needs and the decisions of the staff. After a 6-month period, those patients previously assigned to home care were reassessed by the home care staff to determine whether the staff thought that home care was still needed. This was a clinical assessment and those families whom the staff thought to be no longer in need of home care services were discharged from PHC in order to avoid the continuation of patients in a form of care more intensive than they required. Those patients whom the home care team thought still needed PHC were renewed for an additional 6 months or continued for even longer periods.

Data

Data were obtained primarily from structured household interviews with the mothers of both the standard care and home care groups at three points in time: time 1 (enrollment); time 2 (after 6 months of care); and time 3 (after an additional 6 months). The first interview was scheduled to take place within 2 weeks of enrollment and randomization. This interview covered the pretest of the dependent variables. During the subsequent 6-month period the patient received care through the PHC service (experimental) or standard care (control). Six months after entry, time 2 interviews were conducted; these consisted of variables covered in the time 1 interview, additional utilization data, and portions of the measures of burden and family resources. Regardless of whether or not a home care family remained in PHC after the initial 6-month interval, all families continued in the study and participated in a third and final household interview, which occurred at 1 year after enrollment and covered all the items in time 2, with additional questions at the end of the interview about the nature of the experience with home care, if applicable.

Of the 219 children originally enrolled in the study, 209 completed the initial time 1 interview (104 standard care and 105 home care), 188 completed the 6-month interview, and 182 completed the 1-year interview. A complete data set of all three interviews exists on 174 subjects or 80% of all subjects. Of the remaining subjects, six died and eight moved far away from the geographic region. Comparisons on a large number of demographic and medical characteristics between those with complete data sequences and those who did not complete the sequence demonstrate no significant differences except for a somewhat higher retention of black and Hispanic children than of white children.

All interviews were conducted by experienced lay bilingual interviewers in either English or Spanish, using interview materials prepared in both languages. Hispanic mothers chose the language in which they were most comfortable and all interviews were tape recorded. Open-ended material was checked against the tape recording, coded by a research assistant, and checked by a second staff member. The data reported here are limited to scale scores on five major variables listed below, all of which use fixed-response categories.

Satisfaction with care. This variable assesses the extent to which the respondent feels satisfied with the medical care the index child is receiving. A schedule, based on the work of Ware et al,[9] was developed with modifications making it suitable for use in a municipal hospital setting, with children's medical problems, and with nurses as well as physicians. Cronbach's α for the total score is .88.[8]

Child's Psychological Adjustment. A 28-item version of the Personal Adjustment and Role Skills Scale (PARS) II scale developed by Ellsworth was used to measure the psychological adjustment of the 81 children in the sample who were 5 years of age or over at entry. (In subsequent revisions, the PARS II title is reserved for the adult version, and the child and adolescent version is termed the CAAP. See R. Ellsworth and S. Ellsworth: *CAAP Scale: The Measurement of Child and Adolescent Adjustment.* Palo Alto, CA, Consulting Psychologists Press, 1982.) This measure, designed to be administered to a parent or other significant adult, has a plausible factor structure, has good reliability and discriminant validity, and has been used with minority populations. The scale was chosen because of its psychometric properties as well as its distinctiveness in simultaneously including three dimensions of particular interest in the study of chronic illness: dependency, hostility, and withdrawal. In addition, it assesses anxiety-depression, productivity, and peer relations. The final 28 items used in this study were selected from the original 55-item schedule developed by Ellsworth. The criteria for selection included judged clinical relevance for a population of chronically ill children, extent of variation and discrimination of response in a pretest sample at our institution, and factor analyses provided by Ellsworth. The psychometric properties of the scale have been replicated on the present sample and a factor structure identical with Ellsworth's was obtained. The internal consistency of the total score is excellent (α = .82).

Mother's Psychiatric Symptoms. For the purpose of this study, the mental health of the mother was defined as the variety and flexibility of emotional responses and was measured by the intensity and frequency of maladaptive behavior using the 29-item Psychiatric Symptom Index,[10,11] a shortened version of the Hopkins Symptom Distress Checklist.[12] Items reflecting groups of symptoms, signs, and dispositions are included. Psychiatric diagnosis is not implied, although the items may be consistent with diagnostic entities. The symptom patterns thought to be of interest were: anxiety and depression, anger/hostility (deemed especially appropriate as it may be related to child abuse), and somatization (especially relevant for Hispanic populations). These symptom patterns were selected because they occur with significant frequency in nonpatient samples, and because they are believed to be related to a mother's ability to function in her role. The instrument selected had been used previously with multiethnic disadvantaged urban dwellers and it had a factor structure compatible with the concepts of interest in this study. The structure of this instrument was reexamined on data from the current sample and the results replicated the previously obtained findings for a lower class sample.[13] Reliability analyses using Cronbach's α indicate that the total score has high internal consistency ($\alpha = .93$) in this population.

Impact on Family. The impact on family scale is designed to determine the negative effects of a child's illness on the family. Four dimensions were theorized as relevant and defined through factor analysis and psychometric procedures.[14] There is a total score and four subscores. The total score has a Cronbach's α of .88.

Functional Status Measure. A functional status measure, developed specifically for this study, is designed to tap variation in function among children having a wide variety of chronic conditions and to be sensitive to minor differences in function within a given child over time. The goal of this measure is to describe the morbidity status of the sample. Functional status is defined as the capacity to perform age-appropriate roles and tasks. It assesses behavioral responses to illness that interfere with normal social role performance. Stein and Jessop[3] have described the development and validation of this measure elsewhere. The score used here is the general health status score for children 9 months of age or older.

Comparability of Treatment Groups

Comparability of the home care and standard care groups at enrollment was determined for sociodemographic variables and 29 scales and subscale scores using standard χ^2 tests for ordinal and nominal variables and two-tailed t tests of differences between means for interval level variables. As there were losses from both treatment groups, the equivalence of the treatment groups was also determined on time 1 enrollment data for those who were retained in the sample to time 2 and time 3. There were no significant differences on time 1 enrollment data between either the entire PHC and standard care groups or between those retained in the study and those lost, beyond those that could be expected by chance, for either characteristics of the children, their caretakers, family structure, social context, or pretest scores.

Data Analysis

All data for home care and standard care groups are compared on the 6-month (time 2) and 1-year (time 3) outcome measures using standard analysis of covariance (ANCOVA) procedures with the pretest data as the covariate and looking at the significance (F test) of differences between adjusted mean scores. The homogeneity of regression assumption was tested in all analyses. The *Statistical Package for the Social Sciences* (SPSS) programs were utilized on a DEC20 computer system.

RESULTS

The analysis of covariance results for the comparisons of the home care and standard care groups are summarized in Table 2. The pattern of the means within groups over time also allows for determination of whether or not there has been improvement on a given variable.

Significant differences between the groups at time 2 are found for the mother's satisfaction with the child's medical care and the child's psychological adjustment, with more improvement in home care on both variables. A difference significant at $P = .07$ is also obtained between the groups for the mother's psychiatric symptoms: mothers in the home care group showed improvement while those in the control group grew more symptomatic. There is no difference between the groups in the impact of the illness on the family or the functional status of the child, with the decline in impact scores and increase in functional status scores indicating that both groups improve in these areas over time.

The pattern of significance at time 3 (1 year) replicates that at time 2 for satisfaction with care, impact of the illness of the family, and functional status. The results for the child's psychological adjustment are significant at $P = .08$ at time 3 for the whole group comparison. At time 3, there is no difference between the two groups with respect to the mother's psychiatric symptoms, with both groups showing improvement by the final interview.

TABLE 2. Effects of Pediatric Home Care: Analyses of Covariance*

Measure	Time 2 (6 mo)		Time 3 (1 yr)	
	Standard Care	All Home Care	Standard Care	All Home Care
Satisfaction with care				
Pretest	32.43 ± 4.49	31.95 ± 3.84	32.43 ± 4.49	31.95 ± 3.84
Unadjusted posttest	31.96 ± 4.05	32.90 ± 4.18	32.15 ± 4.26	33.12 ± 4.00
Adjusted posttest	31.83 ± 3.48	33.03 ± 3.59	32.00 ± 3.52	33.25 ± 3.31
No. of children	81	93	81	93
F	4.933		5.867	
Significance of *F*	.028†		.016†	
Child's psychological adjustment (children ≥5 yr)				
Pretest	65.84 ± 9.05	66.94 ± 9.21	65.84 ± 9.05	66.94 ± 9.21
Unadjusted posttest	65.59 ± 9.92	69.76 ± 7.99	65.11 ± 9.82	68.97 ± 7.95
Adjusted posttest	65.93 ± 7.57	69.39 ± 6.10	65.39 ± 8.21	68.66 ± 6.64
No. of children	37	33	37	33
F	4.349		3.240	
Significance of *F*	.041†		.076‡	
Mother's psychiatric symptoms				
Pretest	23.44 ± 15.40	26.46 ± 16.73	23.36 ± 15.32	26.46 ± 16.73
Unadjusted posttest	23.40 ± 17.24	23.28 ± 15.84	20.69 ± 15.56	24.58 ± 16.23
Adjusted posttest	24.76 ± 10.08	22.12 ± 9.27	21.88 ± 10.64	23.54 ± 11.11
No. of children	81	93	81	93
F	3.237		.980	
Significance of *F*	.074‡		.324	
Impact on family				
Pretest	47.03 ± 7.63	48.69 ± 8.94	47.03 ± 7.63	48.69 ± 8.94
Unadjusted posttest	43.96 ± 7.33	46.27 ± 7.91	42.68 ± 7.90	45.04 ± 8.66
Adjusted posttest	44.52 ± 5.34	45.79 ± 5.76	43.23 ± 6.12	44.56 ± 6.71
No. of children	81	93	81	93
F	2.190		1.783	
Significance of *F*	.141		.184	
Functional status: general health (children ≥9 mo)				
Pretest	75.73 ± 16.25	75.87 ± 18.91	75.73 ± 16.25	75.87 ± 18.91
Unadjusted posttest	81.14 ± 15.79	80.24 ± 16.14	81.48 ± 15.79	80.57 ± 17.02
Adjusted posttest	81.16 ± 14.25	80.21 ± 14.56	81.67 ± 14.35	80.40 ± 15.47
No. of children	66	76	66	74
F	.154		.247	
Significance of *F*	.696		.620	

* Values are means ± SD.
† Significant at $P < .05$.
‡ Significant at $P < .10$.

The original hypotheses are outlined in Table 3, and the last two columns show whether the hypotheses are upheld at 6 months and 1 year. As indicated in Table 3, the hypotheses are upheld with respect to three of the five variables at both times (satisfaction with care, child's psychological adjustment, and functional status) and an additional variable (mother's psychiatric symptoms) which approaches significance at time 2. As was hypothesized the children and families in PHC do better than those in standard care on satisfaction with care, child's psychological adjustment, and lessened maternal psychiatric symptoms, while there is no difference between the groups in the functional status of the child. The consistency of the findings across time for satisfaction with care, child's psychological adjustment, and functional status strengthens the results, as does the fact that the results occur in confirmation of the hypotheses.

Not all the children assigned to the experimental group received a year of home care services, a factor that could potentially affect the findings. Therefore, these analyses were repeated eliminating (1) those children randomized to the experimental treatment who failed to receive it because of failure to connect with the PHC team (N = 13) for both

TABLE 2. Hypotheses and Results of Pediatric Ambulatory Care Treatment Study

Variable	N	Hypotheses*	Supported	
			Time 2	Time 3
Satisfaction with care	174	HC > SC	Yes†	Yes†
Child's psychological adjustment	70	HC > SC	Yes†	Yes‡
Mother's psychiatric symptoms	174	HC < SC	Yes‡	No§
Impact on family	173	HC < SC	No§	No§
Functional status: general health	142	HC = SC	Yes§	Yes§

* Abbreviations used are: HC, home care; SC, standard care.

† Significant at $P < .05$.

‡ Significant at $P < .10$.

§ No significant difference.

the 6-month and the 1-year analysis and (2) those who were discharged from the home care service prior to completion of the 1-year interview (N = 27) from the 1-year analysis. In a repeat analysis, restricted to those children who actually received the experimental intervention for the time period being evaluated, the patterns remain very similar. There are no significant differences in the impact of the illness on the family, the child's functional status, or the mother's psychiatric symptoms, and there are significant differences favoring home care in both satisfaction with care and in the child's psychological adjustment. Analysis of the child's psychological adjustment limited to those children retained in the experimental treatment for the full year suggests a dose-related effect. The difference between groups in the child's psychological adjustment at 1 year is significant at the $P = .026$ level, and while those children retained in home care for 1 year had slightly poorer psychological adjustment than other children on their pretests, they had higher scores than all other groups of children at completion of the 1-year treatment.

DISCUSSION

The secondary sequelae of chronic illness have been cited as the cause of considerable morbidity among children.[3] It is therefore important to consider therapies that may minimize these sequelae and maximize the potential for the child to thrive. Many have called for the chronically ill child and his family to receive the services of a generalist who serves as ombudsman, advocate, care provider, and counselor,[15-18] and some have suggested that children with chronic conditions should receive services in special comprehensive care programs.[19] It is clear that considerable portions of care are omitted in existing specialty service arrangements,[20-22] even when those are intended to be multidisciplinary and comprehensive.[23]

The PHC program evaluated here is one model of the type advocated by Messenger and Gliedman[19] and fulfills the basic criteria outlined by the recent conference at Vanderbilt on primary care for children with handicapping conditions.[24] It is unusual to be able to assess such a service in an experimental field trial and perhaps even more striking because the experimental evaluation occurred after 8 years of program existence, during administration by its third director, at a time when none of the original staff was involved on a full-time basis, and when there was considerable staff instability. Therefore, this is a program evaluation conducted in a real-life situation which is least likely to produce an artifactual improvement in outcome. Moreover, the research itself had effects that disrupted some of the usual procedures of the program and were perceived by the PHC staff as minimizing their effectiveness.[25] Thus it appears for several reasons that these findings may be an underrepresentation of the true effects of such an intervention.

Despite these real and potential limitations on the detection of improved outcome, the experimental group did have significantly greater benefits in two and possibly three important areas (satisfaction with care, child's psychological adjustment, and possibly mother's psychiatric symptoms). These should not be minimized for several reasons. First, the significant differences are in the direction predicted by the hypotheses. Second, satisfaction (sometimes viewed as "soft" outcome) has been shown to be related to compliance with medical regimens and hence may be an important variable in predicting improved medical outcomes for those health problems in which benefits of biologic treatment can be clearly documented (eg, control of diabetes). Unfortunately, not all therapies in common usage have demonstrated efficacy. Interestingly, this improvement in satisfaction occurred despite the absence of a differential improvement in health status which has been associated with and thought to explain better satisfaction in previous studies.[26-28] Third, the child's psychological adjustment could only be measured for the 70 children 5 years of age and older at all time periods. This reduction in sample size would lessen the likelihood of finding significant differences between the groups.

In the area of impact on family no differences were found between the groups; while β error cannot be ruled out, other possibilities exist. One is that families may not be able to attribute changes in family life to a child's illness.[29,30] Alternatively, the support offered by the program, which may lessen impact, may be masked or offset by the increased burden of caring for the child and doing more medical and nursing tasks at home, something that was documented to occur.

Questions can be raised about both the choice and direction of the hypotheses. For example, the third hypothesis posited that there would be no difference between the groups on functional status. Those skeptical of home care feared that it might be unsafe and hence thought children would get sicker in this service. Therefore, this variable was introduced defensively to assure that such an effect, if present, would be detected. It was never thought that a program of the type outlined above could ensure improvement in physical health status with many of the types of conditions included.

Ideally, one would like to know the pattern of utilization of medical care by those in the home care and standard care groups and determine whether the greater effectiveness of PHC in psychosocial areas is achieved at greater, equal, or less financial cost than standard care. Although some data regarding utilization remain to be analyzed, the nature of the setting in which the study was carried out, which bills on a flat-fee basis, precludes an optimal assessment of true costs.

An obvious next question involves the identification of the effective ingredient(s) in the PHC program, an issue that cannot be elucidated by the present study. A decision was made prior to the initiation of the study to focus efforts toward determining whether the program as a whole had a differential effect, rather than on defining or quantifying its components. This focus was, in large measure, prompted by the general absence of measured effectiveness in studies of comprehensive interventions and a desire not to unduly disrupt the program and undermine our ability to find effects where possible. Nevertheless, it is now important to determine the cause of improved outcomes when they do exist. A possible explanation of improved satisfaction may be suggested by recent work of Breslau[27] who has shown that continuity of care, such as that provided by the home care service, improves satisfaction among families of chronically ill children more than it does among families of well children.

A key issue is whether home services are an effective component of the intervention, and if so, whether they are substantively important or symbolically important because of the interest and concern manifest by their inclusion. Larson[31] suggests that there may be critical periods when home visiting may make a difference. He showed that home visits initiated prepartum were effective, whereas visits begun after the birth of a child have less effect. One wonders whether visits surrounding a child's illness may occur in a similar sensitive period.

It is intriguing that a result of this programmatic outcome is improved adjustment of the chronically ill child and that this occurs in the absence of significant differential improvement in the perceived impact of the illness on family. In the face of this lack of difference between the groups in impact on family it is not possible to explain the improvements that did occur on the basis of a generalized enhancement in perception of the family's well-being. Similarly, the child's improved adjustment is not accompanied by a report of better overall health status as reflected by functional status. The accentuated improvement in the child's psychological adjustment among the group receiving a full year of home care also warrants further exploration. Additionally other analyses will determine for which subgroups of children (defined either by demographics, diagnoses, or other relevant parameters) the program was most and least effective. While many questions remain to be answered, this study documents that a comprehensive service for children with serious ongoing health problems does have measurable benefits and these improved outcomes warrant further investigation.

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Health Care Services Received by Children With Chronic Illness

Ruth E. K. Stein, MD; Dorothy Jones Jessop, PhD; Catherine K. Riessman, PhD

• The mothers of 209 children with chronic illness who were being treated at a university-affiliated municipal hospital were interviewed in their homes to assess the extent to which their children received health services. Most families received traditional biomedical types of care, but few families had received psychosocial services. Children with the most severe conditions tended to receive more services than others, and receipt of nonbiomedical services was associated with identification of a specific provider. Mothers indicated that, in addition to traditional services, they wanted advice on how to manage the child's condition at home. These results confirm previous findings and suggest that gaps in service provision may be generalizable to children with chronic illness regardless of the setting and diagnosis.
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Determining actual health needs is not a simple matter for the population at large[1] and may be even more difficult for children with chronic illness. It can, however, be assumed that children who experience chronic physical illness and their families have many medical needs beyond those of children without such conditions. In addition to the ordinary care of well children, children with chronic physical conditions may require technically sophisticated and specialized services. These include ancillary supports to help deal with psychosocial issues that surround the physical condition and have implications for the present and future lives of the child and the family.

In 1974, Kanthor et al[2] outlined nine elements of service that seemed to be necessary in the care of children with chronic illness. Although these elements were assumed to have obvious relevance for the proper care of children with chronic conditions, their report demonstrated that many of these services were not being received by families whose children were enrolled in a regional spina bifida center. Later, Pless et al[3] demonstrated similar gaps in the care of a group of children with arthritis at the same medical center. Palfrey et al[4] subsequently showed that many children who received care in four specialty clinics of a major urban children's center lacked primary care services and had additional health problems and symptoms that had never been mentioned to the subspecialists. However, to our knowledge, there have been no studies that document the patterns of care in community-based facilities, which frequently deal with children who have a diverse range of conditions. Moreover, characteristics of the conditions that may be associated with lack of care have not been identified.

The purpose of the present report is to assess the types of services received by children with a wide range of chronic conditions who obtain their care in a large urban community hospital to determine the following: (1) the frequency with which mothers report that their children receive each type of care outlined by Kanthor et al[2] from a health professional, (2) the elements of care obtained outside the health system, (3) the types of care that mothers

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From the Department of Pediatrics, Albert Einstein College of Medicine, Bronx, NY (Drs Stein and Jessop), and the School of Social Work, Smith College, Northampton, Mass (Dr Riessman).

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Reprint requests to Department of Pediatrics, Albert Einstein College of Medicine, 1300 Morris Park Ave, Bronx, NY 10461 (Dr Stein).

believe they need but are not receiving, and (4) characteristics of the condition that correlate with receipt of care.

SAMPLE

The sample included 209 children who met eligibility criteria for a longitudinal study of chronic childhood illness conducted by the Division of Pediatric Ambulatory Care, Albert Einstein College of Medicine, Bronx, NY, and who were seen at a university-affiliated municipal hospital during the period from June 1978 to January 1980. This facility serves children throughout the Bronx and offers a wide array of general and subspecialty services typical of a large municipal hospital center. Criteria for inclusion in the study were the presence of a physical condition that lasted three or more months or necessitated a period of continuous hospitalization of at least one month,[1] age younger than 11 years, residence in the Bronx, need for care beyond that of a well child, and receipt of a portion of care through one of the affiliated hospitals of the Albert Einstein College of Medicine. Additionally, the child could not be moderately or severely retarded, had to be expected to live for the duration of the study year, and had to live in an English- or Spanish-speaking household. Only one child per family was enrolled in the study.

Bilingual female interviewers recruited subjects from the inpatient service and subspecialty clinics. All children were included who came to the attention of the research staff, met the eligibility criteria for the study, and completed the enrollment procedures. A consent form approved by the institutional review committee was signed by each mother.

The sample was heterogeneous with respect to diagnosis. The 209 children had more than 100 different conditions. These diagnoses included, but were not limited to, asthma (N = 76), seizure disorder (N = 26), hemoglobinopathy (N = 13), congenital heart disease (N = 7), malignancies (N = 6), diabetes mellitus (N = 5), and a variety of congenital anomalies, such as meningomyelocele/hydrocephalus (N = 23) and biliary atresia (N = 5). More than half of the children had two or more conditions and, in some cases, as many as nine. All required care at home beyond that of well children, as measured by an overall burden index, which is described further.

Table 1.—Demographic Characteristics of 209 Families at Enrollment in Pediatric Ambulatory Care Treatment Study

Demographic Characteristic	%
Race/ethnicity	
Hispanic	60
Black	27
Other	13
Family type	
Both parents	45
Mother alone	39
Mother with other adult	13
Other	3
Annual family income	
<$5,000	33
≥$5,000-<$9,000	37
≥$9,000	30
Source of income	
Public assistance	55
No public assistance	45
Mother employed	17
Mother unemployed	83
Other household member employed	55
Other household member unemployed	45
Level of education of mother	
<High school graduation	56
≥High school graduation	44

Table 2.—Health Needs and Questions Asked

Area	Question
1. Usual source of care	Is there a place you usually go for care and a particular person you usually see there?
2. Coordination	Does this provider make arrangements if the child needs to see a specialist or talk to other agencies, eg, school, day-care center, medicaid, if that is necessary?
3. General advice	Does anyone give general advice about your child and such things as special schooling, handicaps, behavior problems, and things to expect later in childhood or adulthood?
4. Family risk	Does anyone discuss with you whether the child's illness runs in the family or could occur in other family members?
5. Listen to concerns	Does anyone listen to your concerns about your child and understand the problems of raising a child with an illness?
6. Explanation of illness	Has the child's illness been explained to you?
7. Intercurrent illness	Is there someone you go to when the child has a fever or an ear infection, or something like that?
8. Health care maintenance	Does anyone measure the child's height and weight and talk about development, eating patterns and things like that?

The sociodemographic characteristics of the sample are given in Table 1. The sample was entirely urban, predominantly poor, and composed largely of minority group members.

METHOD

The data were obtained from a home interview conducted with the mother at the time of enrollment in the study, before the intervention. The study by Kanthor and colleagues[1] had used an in-depth interview in which specified topics were covered in an open-ended manner. In the present study, interviews were structured, requiring the interviewer to read each question exactly as written, to check the appropriate response category, or to fill in a short answer. Interviews were conducted by experienced lay bilingual interviewers in either English or Spanish using interview materials prepared in both languages. Hispanic mothers chose the language in which they were most comfortable, and all interviews were tape recorded. Open-ended material was checked against the tape recording, coded by a research assistant, and checked by a second staff member.

In the present study, respondents were asked structured questions about each of eight areas contained in the study by Kanthor et al.[1] These are given in Table 2. Two of those investigators' areas, general advice and future planning, were combined into one item (No. 3). A ninth area included by Kanthor and associates, namely, evaluation and treatment, was excluded from this analysis because earlier studies[4,5] have demonstrated that virtually all patients had received this type of care and because of the complexity of assessing adequacy of evaluation and treatment in a population with heterogeneous diagnoses.

The mothers of patients who reported receiving a given service were asked who provided it. Probes were used to ascertain whether the provider was a specific health care provider, (eg, general pediatrician, nurse practitioner, or subspecialist), family member or friend, or a facility. In instances in which more than one source was mentioned, responses were tabulated to include both the first and second source of care in each of the eight areas surveyed. It was assumed that being able to identify a specific person by name and/or professional role indicated a familiarity with the person who provided care over and above that of being able to name only the facility, eg, the emergency room. Sources outside the health care system were also recorded, coded, and tabulated.

To avoid biasing responses, the mothers had been asked two open-ended questions before the portion of the interview that dealt with services the child received. These questions concerned things they would like to know about taking care of the child or about the child's condition. Those who indicated that there was something they wanted to know were asked what it was. Codes were developed for open-ended questions using Kanthor and colleagues'[4] basic list of categories. Additional codes were developed for responses that did not fit into preexisting categories.

RESULTS

Receipt of Services From Health Professionals

Three fourths of the 209 mothers reported that they had a usual place to go for the care of their child within the health care system (Table 3). Ninety-three percent identified a source of care for intercurrent illnesses. Eighty percent of the children had received health care maintenance services, and 78% of the families had been given an explanation of the child's illness. In sharp contrast with these responses about traditional medical services, only 23% of the families had received general advice from those within the health care system, and only 30% indicated that someone listened to their concerns. Approximately half of the families reported having discussions with providers about whether the child's condition ran in the family. Thus, the majority of families did not receive these less clearly biomedical services.

A related issue is the source of health care services and the determination of whether the family received care from a specific provider. The third column of Table 3 indicates the percentage of families who identified a specific person rather than a facility as providing each service. Only 26% of those who received care for intercurrent illness reported using a specific provider, rather than a facility, for intercurrent illnesses. A substantial percentage (34%) of those receiving health care maintenance also identified the source as a facility rather than a person. In other areas where services had been received from the health care system, a specific professional was usually identified by the mother. While only a small percentage of the families reported receiving advice, counseling, and future planning, those who did report receiving these aspects of care tended to identify a specific provider, rather than a facility, as the source of these services. A consistent distinction seems to exist between patterns of care for the more and the less traditionally biomedical components of care.

Table 3.—Percentage of Patients Receiving Specific Areas of Service From Health Care System

Area of Service	% of Total Sample Receiving Service (N = 209)	% of Those Receiving Services Who Identified Individual Provider
Usual source of care	77	83
Explanation of illness	78	63
Intercurrent illness	93	26
Health care maintenance	80	66
General advice*	23	89
Listen to concerns	30	69
Familial risk	51	81

*Advice about the need for special schools, possible handicaps, behavioral troubles, and things to expect later in childhood or adulthood.

Table 4.—Percentage of Patients Receiving Specific Areas of Service by Source of Service

	% of Patients				
Area of Service	Health Personnel	Health Personnel, Family, and Friends	Family and Friends	Neither	Total
Usual source of care	77	...	...	23	100
Explanation of illness	77	1	2	20	100
Intercurrent illness	91	2	4	3	100
Health care maintenance	79	1	...	20	100
General advice*	21	2	9	68	100
Listen to concerns	24	6	31	39	100
Familial risk	48	3	5	44	100

*For explanation of general advice, see footnote to Table 3.

Receipt of Services Outside the Health System

The second issue addressed was the relative extent of help that respondents received from within or outside the health care system. The degree to which the family identified a source of assistance outside the health care provision system was assessed by categorizing responses, naming the following: (1) health care facilities or providers only, (2) family and friends only, (3) both, or (4) neither (Table 4). It is striking that two thirds of the respondents denied that anyone gave them general advice. A third of those who obtained such advice from any source obtained it from family or friends. Similarly, while 39% reported that no one listened to their concerns, another 31% reported that only friends and family listened to their concerns about raising a special child.

Additional Types of Services Mothers Desired

It can be asked whether the areas defined by physicians[3] bear any relationship to the types of assistance parents of children with chronic illness think they need. Analyses of the open-ended material preceding the structured questions disclosed that almost three fourths (74%) of the respondents had some difficulty understanding the disease or wanted more information about the condition. They reported a desire for further explanations of the

Table 5.—Percentage of Patients Receiving Specific Areas of Service From Health Care System by Severity of Condition

Type of Service	Global Burden Rating* 1 (N = 29)	2 (N = 60)	3 (N = 73)	4 (N = 31)	5 (N = 13)	χ^2 (df = 4)	P	Clinician's Overall Burden Index† 0-115 (N = 128)	116+ (N = 73)	χ^2 (df = 1)	P
Usual provider	66	73	84	87	83	12.17	.02	71	69	4.09	.04
General advice‡	14	22	16	36	46	11.33	.02	16	30	3.12	.08
Familial tendency	28	40	60	56	58	6.13	.19	46	63	5.56	.02
Listen to concerns	34	16	30	42	60	6.12	.19	26	38	3.02	.08
Explanation of illness	78	76	75	90	100	7.84	.11	74	85	2.56	.11
Intercurrent illness	83	90	96	100	92	6.34	.18	91	96	.85	.35
Health care maintenance	76	75	84	77	100	5.12	.27	79	80	.00	1.00

*Range of severity for global burden ratings was one (low) to five (high); the global five-point rating scale indicates the severity of burden the child's condition would impose on any family.

†A structured 44-question instrument that measures the burden caused by medical/nursing tasks, disruption of family routine, psychologic burden of the prognosis, fixed deficits of the child, and added dependency of a child who cannot perform age-appropriate roles and tasks. Range of 0 to 115 indicates low index; 116+, high index.

‡For explanation of general advice, see footnote to Table 3.

illness (25% of respondents) and its cause (21% of respondents), as well as advice about what to expect in the future (19% of respondents) and about new medications and treatments (21% of respondents). However, the most often cited need (requested by 31% of respondents) was advice about daily management of the illness in the context of everyday home life. Mothers wanted to know "how to control" the illness, what brings on symptoms or attacks, and "what to watch for." This was not previously identified as a separate need.[8]

To determine whether receipt of a service reduces or increases the desire for help in that area, the respondents' expressions of areas in which they desired help were examined according to whether that type of service had been received. The types of services about which parents were asked overlapped only partially with the list of types of information that parents volunteered they would like to have. Cross-tabulations of the items that appear on both lists determined if receipt of a given type of service was associated with a continuing desire for that type of service or conversely with a decrease in need for help of the same type. Comparable categories were available for explanations of illness, discussions of whether the illness runs in the family, general advice, and advice on growth and development, and the χ^2 test was used to summarize the results.

The results indicate that parents who have been given general advice by someone are more likely than other parents to want additional advice about special schools and programs (χ^2 = 5.44, P = .02). On the other hand, parents who have had someone explain the illness to them are less likely to want explanations of the cause of the condition than are parents who indicate that they have not had someone explain the illness to them (χ^2 = 3.48, P = .06). There was no relation between having received advice and wanting help about behavior problems (χ^2 = .00, P = 1.0) or things to expect in the future (χ^2 = .54, P = .46). There was also no relation between having someone perform health care maintenance and wanting advice about development, or between having someone explain the familial risk and wanting more discussion of it.

Table 6.—Percentage of Respondents Having Received Each Specified Service by Length of Knowledge of Diagnosis

Type of Service	Length of Knowledge, mo 0-2 (N = 46)	3-12 (N = 48)	13-60 (N = 41)	60-127 (N = 42)
Usual provider (χ^2 = 7.78, P = .05)	78	85	73	90
General advice* (χ^2 = 3.11, P = .37)	16	17	27	29
Familial tendency (χ^2 = 4.73, P = .19)	43	48	53	62
Listen to concerns (χ^2 = 1.50, P = .68)	24	33	29	36
Explanation of illness (χ^2 = 6.78, P = .08)	90	78	68	74
Intercurrent illness (χ^2 = .96, P = .81)	90	91	95	93
Health care maintenance (χ^2 = 1.96, P = .58)	76	85	80	74

*For explanation of general advice, see footnote to Table 3.

Correlates of Receipt of Health Care

Provision of help by the health care system may be related to the severity of the condition or the length of time since diagnosis. More severe conditions and/or longer time since diagnosis may indicate more extensive interactions with the medical care system and allow greater opportunities for the provision of different types of services. These opportunities may not be available if the condition is newly discovered or occurs in a newborn. Alternatively, help that is offered may be received and integrated selectively by the family at different times in the course of the illness. The degree to which health needs of children were met was examined for children by looking at these variables. The severity of illness was assessed by using two measures: (1) a summary burden rating and (2) the Clinician's Overall Burden Index. The latter is a structured instrument that was developed as part of the present project to measure the burden in a given child's care across disease categories.[6] It assesses the level of burden involved in a given child's care and has an internal consistency as measured by Cronbach's alpha coefficient of .70.[7] Internal consistency is commonly used as an estimate of reliability.[7]

Children with high summary burden ratings and high scores on the Clinician's Overall Burden Index received care in virtually all of the hypothesized areas more frequently than other children (Table 5). In both sections of Table 5, the differences are significant ($P<.05$) in two instances. Differences exist at the $P\leq.10$ level in three other instances when the control variable is the global rating and in two additional instances when it is the Clinician's Overall Burden Index. Regardless of the measure, the degree of burden had no effect on the provision of health care maintenance, a service received by very high proportions of the children in the sample. Neither does severity, as measured by the burden index, have any effect on the provision of care for intercurrent illness.

The effect of length of time since diagnosis was weaker and varied with the type of service (Table 6). However, it is noteworthy that the mothers of patients with a longer time since diagnosis were less likely to report having a usual source of care and receiving an explanation of the illness. Length of knowledge of the diagnosis, like severity of condition, seems to have no effect on the provision of care for intercurrent illness or health care maintenance.

COMMENT

The presence of unmet health needs in populations of children receiving care for chronic conditions has been previously reported.[4,5] However, previous reports have examined patients with specific illnesses being treated in well-organized programs in regional centers or in specialty clinics. The patients in these studies represent a cross section of socioeconomic levels. The current study was conducted with a sample that was not in such a specifically focused system, was heterogeneous with respect to diagnosis, and, hence, was more similar to those patients found in community-based facilities. They represent the urban poor and minority groups. Table 7 compares the findings of Kanthor et al[3] and Pless et al[5] with those of the current study. The numbers in Table 7 indicate the percentage of mothers who failed to report services in each area. Despite differences in the study methods, as well as sample populations and sites, and in the potential language and cultural barriers in this municipal hospital setting, the current sample of patients seems to be receiving comparable services in health education and health care maintenance and somewhat more service in acute illness care. However, as might be expected from a comparison of a general population of children with chronic illness and the population in comprehensively organized clinics, the patients in this sample have been receiving less coordination and support. In general, the similarity of the gaps in care is striking and suggests that the earlier findings may be generalizable.

Table 7.—Comparative Data From Three Studies Showing Percentage of Respondents Reporting Services Not Provided by Health Professionals

Area of Service	Source, yr		
	Kanthor et al,[3] 1974 (N = 44)	Pless et al,[5] 1978 (N = 44)	Current Series (N = 209)
Education	31	23	22
Acute illness care	36	18	10
Health care maintenance	19	10	20
General advice/future planning*	77/88	57/64	77
Support	44	20	75
Genetic counseling	48	84	65
Coordination of services	27	29	54 (medical), 76 (other)

*For explanation of general advice, see footnote to Table 3. General advice and future planning were combined into one area in the present study.

The fact that family and friends provide a significant amount of advice is an important issue that is often overlooked by health professionals. While family and friends are no doubt the best providers of emotional and social support, questions can be raised about the adequacy of their knowledge as the sole basis for advice. Specialized prognostic and referral information may not be available to them unless they are included in discussions with professional personnel in the health care provision system.

One might question whether a reliance on nonprofessional social support structures is a reflection of a lack of contact with the health care system. However, this sample of patients had close recent contact with medical care: 73% had been hospitalized within the last six months, and most had been seen within the two weeks before the interview. Moreover, 76% of the mothers reported that they had access to the child's health care providers by telephone. Still, these mothers perceived that many of their concerns were addressed solely by nonprofessional sources.

The fact that respondents who named a provider also perceived that someone listened to their concerns or gave advice suggests a relationship between these aspects of care and the personalization of services. This poses questions about the overall opportunities for families to raise issues within the health care system, as well as the skills of providers in listening and responding. Adler et al[10] reported that chronic illness and psychosocial issues are among the most difficult and anxiety-producing areas for house staff and are also the least improved during the internship. Pediatricians frequently cite the desirability of delivering comprehensive services to children with chronic illness; nonetheless, there still seems to be room for considerable improvement in the training of pediatricians to perform these functions and meet the needs of families.

It is important to consider the relationship between the lack of certain types of help and expressions of need of parents. The data suggest that the provision of some types of help, ie, explanations of illness, may eliminate the perceived need for more help of that type, while the provision of other types of help may increase the need for further types of assistance, ie, advice about the future and special programs, and, finally, may not influence the degree of desire for other types of help in any way, ie, health care maintenance. These findings suggest that fears of delivery of services, leading only to more demands for services, are not well founded.

The observation that children with the most severe conditions are more likely to have received a variety of services than those with less severe conditions conform to clinical expectations. However, these findings should not lead to complacency. Sizable segments of even those children with the most severe conditions are not receiving care in many of the areas of theorized needs. Moreover, in view of concerns about the perceived vulnerability of children with minor or past illnesses[11] and the possibility that children with marginal illness[12] are at risk for psychosocial sequelae, there is reason for concern about the lack of services received by those children with less severe illnesses who are perhaps in as much or more need for some services than children with the most severe illnesses.

The main conclusion is that children with a wide variety of conditions do not receive services in all the areas of importance. Moreover, in this series, as in earlier reports, there was a significant differential in the provision of strictly defined medical services and supportive services. If comprehensive care is needed by the family with a child with chronic illness and nonbiologic factors influence health outcomes, better ways must be found to provide broader and more effective services for children with chronic illnesses.

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VANDERBILT UNIVERSITY
NASHVILLE, TENNESSEE 37212
TELEPHONE (615) 322-7311
Institute for Public Policy Studies • 1208 18th Avenue South • Direct phone 322-8505

May 2, 1985

Honorable George Miller, Chairman
Select Committee on Children, Youth,
and Families
385 House Office Building Annex 2
Washington, D.C. 10515

Dear Congressman Miller:

We appreciate the opportunity to submit written testimony for the record of the Select Committee's hearing, "Families with Disabled Children: Issues for the Eighties."

The enclosed article summarizes the findings of a study, "Public Policies Affecting Chronically Ill Children and Their Families," that has been underway at Vanderbilt University since mid-1980. Our study deals with the neglected needs of children with severe chronic illnesses, such as cystic fibrosis, hemophilia, leukemia, and heart disease.

We believe that fresh attention to chronically ill children and their families from policymakers and professionals in health, education, and health care financing is timely for at least two reasons. First, dramatic advances in medical technology mean that many of these children, who died young in earlier years, now survive into young adulthood. They are an increasing proportion of the population in health care services and schools. Second, children with severe chronic illnesses use a large portion of the resources spent on health care of all children. Chronic conditions account for one-third of hospital days used by all children, and the cost of care of children with severe chronic health conditions is triple the average cost of care of other children. In spite of the heavy burdens these children and families carry, their increased prevalence, and the high cost of their care, the policies of health care institutions, schools, social service and mental health agencies, insurance companies, and other large organizations have not kept pace with the needs of chronically ill children and their families.

The Vanderbilt study presents findings and recommendations concerning policies in four areas: organization and financing of health services, chronically ill children in schools, training of professionals, and research. We would be pleased to provide additional information on these topics.

Thank you very much for your interest in families with chronically ill children, and for your leadership in helping to focus public attention on them.

Sincerely,

James M. Perrin

James M. Perrin, M.D.
Senior Research Associate

JMP/mdw
enclosure

Special Report

Chronically Ill Children in America

NICHOLAS HOBBS, JAMES M. PERRIN, HENRY T. IREYS, LINDA CHRISTIE MOYNIHAN, and MAY W. SHAYNE

ABSTRACT Excerpts from a 161-page paper entitled "Chronically Ill Children in America: Background and Recommendations," are provided. The paper is the preliminary report of the project, "Public Policies Affecting Chronically Ill Children and Their Families," at the Center for the Study of Families and Children, Vanderbilt Institute for Public Policy Studies, Nashville, Tenn. Excerpts presented here focus on the background and policy issues, while the unabridged paper includes numerous recommendations.

Background

Significance of the Problem

Children who suffer from severe, chronic illness are a neglected group in our society. Their suffering, the heavy burdens they and their families bear, the human resources lost to us all are matters largely unknown to the general public. Chronically ill children live out their lives in a twilight zone of public understanding. As a consequence, our nation, ordinarily attentive to problems of children and families, has lagged in its response to the urgent needs of children with chronic illnesses.

Eleven diseases representative of the severe chronic illnesses of childhood have been examined closely: juvenile-onset diabetes, muscular dystrophy, cystic fibrosis, spina bifida, sickle cell anemia, congenital heart disease, chronic kidney disease, hemophilia, leukemia, cleft palate, and severe asthma. The eleven conditions serve as "marker" diseases, that is, they have characteristics that make them representative of the total range of such illnesses. Considered separately, each disease is relatively rare and occurs in a small percentage of the childhood population. Taken all together, however, perhaps a million children are severely involved and another nine million have less severe chronic illnesses. In considering a million children with severe chronic illnesses, we also refer indirectly to at least three million family members burdened with caring responsibilities, affected by anxiety and sometimes by guilt, strapped by unpredicted expenses and possibly economic ruin, and facing an uncertain future that often includes the premature death of the child.

Chronically Ill Children as a Class

Chronically ill children can be considered as a class for the purpose of organizing services and allocating resources. The special needs of severely and chronically ill children and their families cannot efficiently and effectively be met simply by extending to this group policies that are efficient for children with routine illnesses, with acute or even fatal illnesses, with stable handicapping conditions (such as mental retardation), or with mild chronic illnesses such as allergies, transient asthma, and minor gastrointestinal problems.

For several reasons, there has been a tendency to regard each chronic illness separately. Among the reasons are the physiological diversity of the diseases, the variation in the expected length of life, and the diversity of treatments. A result is that each disease has its corps of specialists, its affiliation with specialty clinical centers, its advocacy group, and its champions in the Congress and state legislatures, each competing with the other for scarce funds.

From a policy perspective, however, the diseases have more in common with each other than they do with other illnesses of childhood. We emphasize that not always, but in general, severe chronic illnesses of childhood share the following characteristics. Most of the diseases are costly to treat. Direct medical treatment costs, including hospitalization, may run high, and long-term care may be costly, too: blood and blood products, insulin, syringes, special diets, drugs, orthopedic devices, transportation, long distance telephone calls, oxygen, control of environmental temperature, glasses, hearing aids, special schooling, and nursing care provided professionally or by family members and friends. Most of the diseases require care over an extended period of time; thus costs mount steadily. In acute diseases, costs may be high but for a short period. By contrast, severe chronic illnesses have both periods of brief high costs plus the continuing costs, never low, for a long period of time. The costs of these diseases may be so great that a family can be made bankrupt, insurance may be impossible to obtain, and employment opportunities for parents and family members may be severely curtailed.

Most of the diseases require only intermittent medical care, at the time of diagnosis and the establishment of a treatment regime, at subsequent routine

About the Report . . .

CONSERVATIVE estimates indicate that one million children and teen-agers have a severe chronic illness. Perhaps five times as many have some degree of chronic illness or disorder. The burdens on children with severe, long-term illnesses and on their families can be immense.

To examine these problems, a major investigation was undertaken at Vanderbilt University. The project, "Public Policies Affecting Chronically Ill Children and their Families," was initiated in July, 1980. The project addressed these broad questions: what are the policy-relevant needs of chronically ill children and their families, and what are the major ethical, political, and economic forces that shape those programs? What might be done to make existing policies work, and what new policies might be developed for a reasonable, resource-constrained, public response to the needs of chronically ill children and their families?

The project selected 11 specific diseases and disorders to examine closely: juvenile diabetes, muscular dystrophy, cystic fibrosis, spina bifida, sickle-cell anemia, congenital heart diseases, chronic kidney diseases, hemophilia, leukemia, cleft palate, and asthma. These are intended to represent the wide variety of chronic childhood illnesses. The study also examined existing and proposed public programs that affect these children, including Title XIX of the Social Security Act, the Education for All Handicapped Children Act of 1975, the Developmentally Disabled Act of 1975 and Amendments of 1978, and the Maternal and Child Health Block Grant.

The study had the benefit of several advisory and consultative groups, including a National Advisory Committee, a consortium of researchers doing empirical work on chronic childhood illnesses, a Washington-based federal interagency panel, a group of national disease-oriented voluntary associations, and an informal group of parents of chronically ill children. In addition, approximately 40 papers were commissioned from experts on a wide variety of topics, including specific disorders, professional services, prevention, the history and current status of public and private programs, and financing of health care for chronically ill children.

The overall goal of the project was to develop specifications for a national policy responsive to the needs of chronically ill children and their families. While the project addressed current federal and state government initiatives, its primary vantage point permits a long-term perspective.

checks, and in periods of crisis. Thus the daily burden of care, day after day, week after week, year after year, falls on the family. Our society is organized to take care of many kinds of handicapped people, young and old, but not the chronically ill child. Formal resources for the daily out-of-hospital care of such children are almost nonexistent.

The future course of all the diseases is highly unpredictable. The uncertainty thus generated creates great psychological problems for the child and his family. Most of the diseases are accompanied by pain and discomfort, sometimes beyond appreciation by the normal individual. Furthermore, most of the diseases require treatments that in themselves are arduous, often painful.

The integration of medical care, not normally a problem, takes on serious proportions when severe and chronic illness of children is involved. The integration of primary, secondary, and tertiary care is essentially nonexistent. Primary care physicians uncommonly see a child with each of the marker diseases. There may be difficulties in early identification and referral, in allocation of responsibility for continuing care, and for coordination among health providers and schools.

Some states provide treatment for sickle cell disease, some do not; some provide treatment for the complications of diabetes, others do not, thus requiring parents who are fortunate enough to be informed to move to communities where there are tertiary care centers or to states that have policies providing assistance to children with particular diseases. And our nation as a whole simply does not provide, at a cost manageable by most parents, the resources it takes to treat a child with a severe chronic illness.

Advances in Health Care and Public Programs

Dramatic progress has been made in preventing some diseases, in bringing others under at least a measure of control, and in actually curing some children with certain diseases that were formerly incapacitating or lethal. Much of the progress has resulted from research leading to new knowledge and from technological developments leading to improved treatment techniques.

Examples of achievements in acquiring knowledge and then in putting that knowledge to work through enlightened public policies are: the discovery in 1922 of insulin, enabling the control of juvenile diabetes; research at mid-century leading almost to the elimination of three major disabling conditions of childhood—poliomyelitis, tuberculosis, and rheumatic heart disease; progress within the last two decades in treating renal disease through transplants and dialysis; development of surgical techniques to alleviate some heart conditions and neural tube defects; advances in the treatment of leukemia with chemical and radiation therapies, treatment of hemophilia with the development of cryoprecipitate, development of means to detect various fetal anomalies *in utero* making early intervention possible, and genetic typing and counseling which can improve family planning and reduce the incidence of some chronic illnesses of childhood.

The scientific and clinical achievements have been paralleled in many instances by the development of social structures. They include: the establishment of the Crippled Children's Service in 1935; mandatory immunization against poliomyelitis and other childhood illnesses including public expenditures to insure availability; reimbursement for health care for children through Medicaid, Supplemental Security Income Disabled Children's Program, and Medicare (for end stage renal disease treatment); the Developmental Disabilities Program, extended in the later 1970's to include children with severe and chronic illnesses; Public Law 94-142, the Education for All Handicapped Children's Act, which includes chronically ill children in its definition of handicapped children; basic biomedical research on severe chronic childhood illnesses through the National Institutes of Health, and registers to determine correlations between environmental hazards and birth defects and chronic illnesses.

Chronicity and Severity: Definitions

A general definition of chronic illness is a condition which interferes with daily functioning for greater than three months in a year, causes hospitalization of more than one month in a year, or (at time of diagnosis) is likely to do so.

While the meaning of chronicity can be rather readily agreed upon, defining *severity* is a much more complex matter. There are simply no good reference points that find ready acceptance. For some of the chronic illnesses here considered, there is a strong inclination among physicians to refuse to assess severity at all, at least not on a physiological basis. For example, either a child has juvenile-onset diabetes or he hasn't, and how well he may be getting along at any particular time is more a reflection of the quality of care and compliance rather than of severity.

For the purposes of this inquiry into public policies affecting chronically ill children and their families, we advance five criteria to assess the severity of impact of an illness, in addition to available criteria of physiologic severity:

- The illness places a large financial burden on the family. For the diseases considered here, out-of-pocket medical cost may exceed ten percent of family income after taxes;
- The illness significantly restricts the child's physical development. Many of the children here considered will be well below normal height and weight as the result of the illness.
- The illness significantly impairs the ability of the child to engage in accustomed and expected activities.
- The illness contributes significantly to emotional problems for the child as expressed in maladaptive coping strategies.
- The illness contributes significantly to the disruption of family life as evidenced, for example, in increased marital friction and sibling behavior disorders.

Defining chronicity and severity on a generic basis to serve public policy purposes is hazardous. The definitions we propose emphasize the social impacts of the diseases in an effort to broaden the conventional disease-oriented definitions. Perhaps most important in considering severity is the recognition that these criteria identify very different groups of children and families. Children with the most physically debilitating arthritis, for example, may have far less emotional problems from the illness than have children with milder diseases.

The Epidemiology of Chronic Childhood Illness

The dramatic medical advances of the past few decades have meant that many children who would have died previously of their chronic illnesses now survive to young adulthood. For almost all childhood illnesses, there is little evidence of changing incidence—that is, the number of new cases appearing in a population of stable size. Furthermore, there is evidence that most potential gains in longevity have already occurred. Thus, the number of children with chronic illnesses is presently mainly dependent on the number of new children in the population; and with a stable (rather than growing) child population, the numbers of children with chronic illnesses will also be stable.

About 10-15% of the childhood population has a chronic illness. Among chronically ill children, about 10% (or 1-2% of the total childhood population) have *severe* chronic illnesses. With the marked decline in morbidity and mortality from infectious diseases among children, and with the increasing survival of children with severe chronic illnesses, the 1-2% have become a much larger part of pediatric practice.

The Organization, Costs and Financing of Health Services for Chronically Ill Children

Organization of Services

Diversity and fragmentation characterize the organization of services for chronically ill children. There is tremendous variation in the care families receive, based on such characteristics as the interest of the specialists in an academic center, the urban or rural nature of the community, and the organization of governmental services, especially Crippled Children's Services. In some areas, a broad variety of family support services are available; in others, available services are limited to medical and surgical interventions.

Families often identify great frustration from the fragmentation of services. They may see one or more specialists a distance from their home; among the specialists, there may be disagreement about plans for the child. Especially for children with multiple handicaps, arranging to be Monday morning in the cardiology clinic, Tuesday afternoon in the neurology clinic, and on Thursday, in the orthopedist's office becomes itself a major management problem.

Despite greater availability, access to adequate specialty medical services is a problem in some communities. Most chronic conditions of childhood are rare and thus community pediatricians and other primary providers, despite the quality of their training, may have little recent experience with an unusual malignancy, severe renal disease, or hemophilia in their practice. Similarly, despite the quality of nursing staff, the hospital with just a few hundred deliveries per year will have very little experience with conditions which occur in perhaps 1 in 10,000 live births. Not only may identification be a complex issue, but referral may be a problem as well.

Access to nonmedical services is highly variable. Some communities may have excellent, comprehensive programs for children with specific health problems, such as the comprehensive hemophilia centers in some areas. In other locales primary care providers offer coordination which assures the availability of a broad range of nonmedical services to families of children with chronic illnesses. The emphasis on medical and surgical care, to the neglect of other services for families, can have a great impact on a child's development and functional abilities. As an example, a child undergoing corrective cardiovascular surgery needs attention not only to his medical and surgical care but also to his schooling. What can be done to diminish his falling behind his classmates; what plans should be made for his activity when he returns to school; are homebound teachers appropriate for a period of time?

Such services can be provided in many ways. Yet the fundamental problem in providing many of them is the lack of reimbursement for the services. Genetic counseling, as an example, is often dependent upon federal research or service support, and with cyclical variations in the support, genetic services may come and go in a relatively brief period of time.

Costs of Care

For most children in the United States, health care costs are small. Average yearly health expenditures for children not living in institutions were only $286.07 in 1978. This average figure, however, disguises a distribution that is extraordinarily skewed. Most children incur minimal health care expenses; relatively few require care that costs an enormous amount. For example, only 5.4 percent of persons under 17, many of whom were chronically ill, were hospitalized one or more times in 1978, at an average cost of $1,920. The rest of the childhood population had no hospital expenditures at all. There are also many chronically ill children in the 2 percent of the nation's population that uses over 60 percent of all inpatient resources each year.

The typical pattern of a high-cost childhood chronic illness involves a series of out-patient treatments and hospitalizations over many years together with routine daily home-care or self-care procedures. This pattern generates many obvious medical costs, for hospital and physicians, medications, lab and X-ray services, and often for such services as physical therapy or social work. Many costs not easily categorized or assessed are also generated; these include transportation costs, extra telephone costs, costs associated with time lost from work or school (often referred to as lost opportunity costs), costs for special diets, and emotional costs associated with increased worry and stress within the family. For each illness the specific medical and social-emotional costs will differ, but for almost every family, both types of cost will be major factors in the financial picture.

Though chronically ill children represent a segment for society for which health care costs are disproportionately high, information available on the costs and financing of services for these children is sparse. For example, no studies are available to enable comparisons across many illnesses and that also take account of the wide range of family needs related to the illness. Instead, most studies focus on specific illnesses and generally on medical services, excluding other services equally relevant to care but often delivered outside of medical settings.

Financing of Care

The system for financing health care in this country is a potpourri of federal programs, state programs, and private insurance arrangements. The complexity of the system is particularly frustrating for parents with a child whose existence is dependent both on specialized medical procedures and on general health services. While most chronically ill children have a large portion of their medical care supported by some third-party arrangement, there remain large gaps in coverage. For some families these gaps can be financially ruinous. We present below a discussion of the six primary sources of payment for health care (broadly defined) of children with chronic illness: private insurance companies, disease-oriented voluntary associations, Medicaid, state Crippled Children Service programs (CCS), special state programs, and out-of-pocket monies.

• *Private Health Care Insurance.* Approximately 75 percent of the nation's children are covered by some form of private insurance. Most children (68 percent of all children) receive benefits under group plans, usually covered as dependents of employed parents. These general figures might suggest that most of the nation's children are adequately protected. A closer look, however, reveals several major shortcomings of private health care insurance, particularly in relation to chronically ill children.

First, private health care insurance is actually medical care insurance. Private plans are designed to cover hospital and physician costs, some lab and drug costs, and a few additional services. They do not cover many costs that families with a chronically ill child will generate, including costs of transportation, home renovations, compensation for time lost from work by parents, custodial care, or counseling.

A second serious drawback of private health care insurance involves the various exclusions embedded in most plans.

Perhaps the most important limitation of private health care insurance is simply the fact that it does not cover many Americans; it especially does not cover children who have limitations in activity and who live in families whose income is below the poverty line. Of these children (numbering about a million), only 17.5 percent are covered by private insurance. The rest are either uninsured or covered under public programs. Furthermore, the number of children, chronically ill included, who are not covered by private insurance tends to increase substantially during periods of high unemployment, when families lose coverage under group plans and cannot afford the costly premiums of an individual plan.

• *Medicaid.* The largest health care financing program that involves children is the Medicaid program, also known as Title XIX of the Social Security Act. (Medicare involves a larger number of dollars but touches only a small group of children: those with end-stage renal disease.) Jointly funded by federal and state governments, Medicaid requires all states to pay for certain services for low income families and allows states to pay for any of an additional 27 services. Eligibility requirements, in many states, are tied to the nation's major welfare program, the Aid to Families with Dependent Children (AFDC) Program. In these states, to be eligible for Medicaid, a family must first be enrolled in the AFDC program.

Some states have elected the "medically needy" option, an important one for chronically ill children. Under this option, families with dependent children or with one absent, unemployed, or incapacitated parent can qualify for Medicaid even if the family income is above the Medicaid cutoff point, but only if the family's income falls below the cut-off point when medical expenses are subtracted. Even in states that offer this option, actual implementation has been spotty.

Many chronically ill and disabled children living in low income families are not eligible for Medicaid. Forty percent of all the nation's disabled children in poverty are not eligible for Medicaid. Twenty-two states have Medicaid programs that cover at least half of the low income handicapped children; 27 state Medicaid programs do not cover even half of this population. If a low-income chronically ill or handicapped child is eligible for Medicaid, it is likely that the program will pay for only some of the services that he or she will need.

• *Crippled Children's Service (CCS).* The CCS program started in 1935 and was the only major public source of support for the care of low-income chronically ill children until the early 1960's, when Medicaid and a variety of categorical programs began. The original legislation established federal grants for states that states would then match.

In August 1981, Congress established the Maternal and Child Health Block Grant and in so doing removed all federal statutory requirements for a state CCS agency. In most states, CCS agencies continue to exist because of state legislation but they all have substantially less federal monies (although not necessarily less state monies). In these states, the CCS program still plays a major role in the care of chronically ill children. It sets and disseminates standards of care, provides for a fairly broad set of services, and covers children from a wide range of income levels. At its best, the CCS program represents an arena in which both the organization *and* the financing of care merge. It is the only broad-based child health program to have influence over both sides of the child health care coin.

The CCS programs have provided much care to many children with chronic illnesses. About $280 million dollars were spent by CCS agencies in 1979; of this amount, 31 percent ($86 million) were federal monies. CCS programs served about a million children in 1979. Data from a recent survey show that in 1980, state CCS programs served 0.91 percent of the nation's children, compared to 0.33 percent in 1948.

• *Disease Oriented Voluntary Associations.* Almost every childhood chronic illness has an associated advocacy group. The origin, scope and available resources of these organizations vary widely. For example, the Muscular Dystrophy Association spent $56.6 million in 1979, the Cystic Fibrosis Foundation spent $11.6

million in 1980, the Leukemia Society $3.8 million in 1980.

These organizations also allocate varying amounts of money to medical services, patient education and training. As a whole, they tend to pay for services that are not reimbursable within the usual system of care, such as special prostheses, recreational activities, or transportation. There is little specific information available regarding how many children are served or how much is spent per child by the voluntary foundations.

Perhaps the most important role that they play, however, is one of advocate. In the past they have supported state CCS programs, often persuading state legislatures to spare the CCS program. For this reason, these organizations may be crucial actors over the next few years, as state legislatures exercise the freedoms given to them by the Maternal and Child Health Block Grant. On the national level, they have often played a critical role in supporting Federal research expenditures in their areas of interest.

- *Out-of-pocket expenditures.* Regardless of the type and extent of coverage that parents may have for their chronically ill child, out-of-pocket expenditures can be high and unpredictable. Families with a child with asthma spent an average of 14 percent of family income on medical costs. In a survey in 1980, the Cystic Fibrosis Foundation found that 20 percent of the respondents reported out-of-pocket costs greater than 30 percent of family income, more than half the respondents said that these expenses were greater than 10 percent of family income. A study of families with children with spina bifida revealed that the average out-of-pocket expenses were 12 percent of the family income. When income loss and nonmedical costs were included, out-of-pocket expenses were 25 percent of family income.

- *Special state programs.* Prior to the introduction of the Maternal and Child Health Block Grant, the federal government had a series of categorical grants to states for child health programs, several of which related directly to chronically ill children. The Hemophilia Treatment Center projects and the Genetic Disease programs are two examples. Although the monies involved in these programs tended to be small, they often provided important seed or ancillary money for state-initiated model programs. In 1980, state hemophilia centers, designed to provide comprehensive care to patients living in an identified region, spent almost $8 million. In fiscal year 1979, the federal government appropriated $11.7 million to the Genetic Disease Program.

These federal programs do not exist as independent programs any longer but there are many state programs, offspring of the federal initiatives, that are continuing. In addition, several diseases have associated state-initiated programs. There are, for example, cystic fibrosis programs operating in several states, developed usually from advocacy efforts spearheaded by local chapters of the Cystic Fibrosis Foundation. There are few data on any of these state-based categorical programs, or on the number of children and families that they serve. Yet, in some states they represent an important, albeit small, source of support for health care of chronically ill children.

Principles for Public Policy

Policy concerning chronically ill children should address the gaps between the special needs of the children and their families and the characteristics of the health care system. The project has identified certain basic principles which should underlie policy, regardless of specific organizational and program characteristics.

- Children with chronic illnesses and their families have special needs which merit attention, beyond that provided to the health needs of able-bodied children. Improvements in health services in general will improve the lot of chronically ill children, and policy development for chronic childhood illness should be integrated with other developments in national child health policy. Nonetheless, the special needs common to most children with chronic impairment will continue to need special attention in public policy.
- Families have the central role in caring for their own members and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development.
- Services should be distributed in an equitable and just fashion, specifically excluding from the distribution formula such nonfunctional characteristics as race, sex, and socioeconomic class.
- Policy should ensure that a broad array of services is available to families with chronically ill children—beyond the usual medical-surgical or health services.
- Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness, and emphasis on collaboration.
- Chronically ill children should stay on task in school to the greatest degree possible. Schooling is the main occupation of young people, and the interference of illness and its treatment with educational activities should be diminished.
- The public commitment to sound basic research has resulted in tremendous advances in the health of chronically ill children. Policy should encourage the continuation and expansion not only of biological re-

search, but also of psychological, biosocial, and health services research related to chronic illness in childhood.

Issues to be Considered for Change in Existing Policies and Programs

Issues: Organization of Services

- The specialization that has improved the medical outcomes for chronically ill children has resulted, ironically, in fragmentation of medical services. The lack of coordination of services, not normally a problem in the care of children with acute illnesses, takes on serious proportions when there is severe chronic illness.
- The diverse providers who treat an individual child infrequently coordinate their efforts. Caregivers may change over the long haul of the illness and its often complex treatment. Families often lack supportive counseling in the care and management of the child with chronic illness.
- Public programs such as those supported by the Crippled Children's Service, Medicaid, and the federal research agencies, provide many essential services to chronically ill children. Yet they often favor the provision of high technology services (usually at high cost) and neglect relatively the broad base of services needed to maximize child functioning and family potential.

Issues: Costs and Financing of Services

- Children with chronic conditions, particularly those with functional disabilities, require much greater than average use of hospital and ambulatory care. In 1977, chronic conditions accounted for 36 percent of total hospital days for all children less than age 15 in the United States. Similarly children limited in activity had greatly increased use of hospitals and visited the doctor more than twice as much as other chronically ill children.
- Public programs account for half of all expenditures for the care of chronically disabled and chronically ill children. Clearly the combined effect of simultaneous reductions in these programs—Medicaid, Medicare and the Maternal and Child Health Block Grant (Crippled Children's Service)—is very serious for chronically ill children.
- The distribution of payment for the medical care of chronically ill children is capricious. There is great variability of financial coverage by income, condition, severity, type of services and geography. The gaps in coverage are of several types:

  —Gaps in benefits. Many programs fail to reimburse for services used frequently by chronically ill children—transportation, social services, home care materials, and genetic counseling.

  —Gaps in populations covered. 10% of all children with functional limitations have no insurance, public or private, and 20% of low income children with functional limitations are uninsured.

  —Gaps in public programs. Medicaid covers only 25 percent of the disabled child population and only about 60 percent of disabled children below poverty. State variation in Medicaid eligibility and scope of coverage for disabled children is tremendous.

  —Large variations exist between CCS programs in numbers of children served, generosity of state programs and conditions eligible for treatment. The Supplemental Security Income program, another important federal program for the disabled population, covers few children; only 5% of SSI beneficiaries are children.

  —Gaps in private programs. The role of private voluntary health associations in financing care for disabled children is limited to "insurors of last resort."

- Many of the nation's children are not covered by private insurance, and chronically ill children are almost twice as likely as other children to lack this coverage. While private insurance does not cover 25% of *all* children, it does not cover 40% of *disabled* children.

Issues: Schools

- Education serves a number of important functions in all children's lives, and its significance for children who have special problems cannot be overestimated. Many chronically ill children evidence no unusual learning problems but many require medical and physical accommodations to participate in school. Under P.L. 94-142, they need "related services" without needing "special education"; yet by definition there can be no related services without special education.
- Chronically ill children may need specialized instruction (e.g., vocational and career preparation, or even adaptive physical education, nutrition, and care of appliances) in addition to instruction in traditional academic areas. These needs are considered by many teachers and administrators to be outside the purview of the public schools. Professional preparation programs for handling medical matters in the classroom are unavailable for the most part.
- Teachers' attitudes regarding expectations for academic achievement by chronically ill children often result in exaggerated deference to the medical implications of a child's handicap. The teacher, the parent, and the physician may have different and sometimes incompatible goals for a chronically ill child.
- Development of plans for children with special

health needs is limited too often by calling for services that are available already in a school system rather than for services the child actually needs. Costs to local education agencies, which have assumed the provider functions, are cited as a deterrent to provision of a broad range of health services that may be needed.

- A major educational problem of chronically ill children is frequent or occasional interruption in school attendance, from prolonged hospitalization, regular weekly treatments, or unpredictable three or four day absences. Current home and hospital school programs, often the only means of providing educational services to sick students, are characterized by great diversity in rules, requirements, and quality. Rigidity in absence requirements for eligibility for home programs and brief length of teacher time on a weekly basis (most states require only three hours per week) illustrate some of the problems.
- The need for supportive services in school complicates educational placement and programming decisions for chronically ill children. Service needs may include special diets (for students with asthma, diabetes, or advanced kidney disease), physical therapy and special transportation (for students with rheumatoid arthritis), special physical handling (for students with spina bifida or muscular dystrophy), social work and liaison services, counseling, and in-school administration of medicines and treatments such as catheterization.
- Schools have limited health services for all children, and few education authorities have developed and implemented specific policies and program health standards for children with special needs.
- Chronically ill children in school have great need for emotional support and opportunities to experience normal peer relationships. Some of the obstacles to meeting these needs include:

  —erratic attendance patterns
  —maladaptive social behavior
  —embarrassing side effects of specific diseases
  —isolation due to equipment needs or geographic location.

- Perhaps the most important obstacle is the unavailability of support for parents in coping with chronic illness.

Issues: Research

- The dramatic improvements in the treatment of many chronic illnesses in the past quarter century have in large part come as a result of a sizeable investment in basic biomedical research, mainly through the National Institutes of Health.
- Support for basic biomedical research has plateaued in the past few years, diminishing the rapid growth in new knowledge characteristic of the previous two decades.
- Support for basic research in other disciplines critical to the needs of families with chronically ill children has been far less generous; investment in behavioral sciences research represents a minimal percentage of the NIH effort in chronic illness. Even less support has been available in such areas as health services and nursing science research.

Issues: Training of Providers

- Most health providers, regardless of discipline, have limited experience with chronically ill children during training. Pediatricians, health professionals with perhaps the greatest direct experience with childhood illness, are mainly exposed to the acute exacerbations of chronic conditions and only occasionally to the long-term problems and family aspects of chronic childhood illness.
- Public health practitioners provide leadership of Crippled Children's and related programs. Yet their training is often divorced from the places where chronically ill children and their families seek health care. The separation of public health people from the clinical realm has led to some of the fragmentation of services for children and diminished the likelihood of effective public-private collaboration in program development.
- Faculties of key professional schools (e.g., medicine, nursing, psychology, social work) rarely include members whose academic focus has been the broad problems affecting families with chronically ill children. Faculties may include many disease specialists, but rarely generalists interested in chronic childhood illness, its coordination or family implications.

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Dr. Perrin served as principal investigator and Dr. Ireys co-principal investigator for the project. Perrin is asst. professor of pediatrics at Vanderbilt University. Ireys is asst. professor of pediatrics and psychology at Albert Einstein College of Medicine.

Linda Moynihan is research associate at the Institute for Public Policy Studies, Vanderbilt University, Nashville, Tenn.

May Shayne is research associate and liaison officer for the Institute for Public Policy Studies at Vanderbilt University.

Nicholas Hobbs is deceased.

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Address: M.W.S., Center for the Study of Families and Children, Vanderbilt Institute for Public Policy Studies, Vanderbilt University, 1208 18th Ave. So., Nashville, TN 37212; (615) 322-7311.

CHAPTER 1

Early Childhood Intervention Programs

Donald J. Stedman

In 1972, Secretary of Health, Education and Welfare Elliott Richardson commissioned five educators[1] to review the effectiveness of "early education intervention" programs. One of the principal concerns which prompted the study was the apparent difficulty of moving small, successful, research programs into more widespread practice, a typical problem in American education. Special focus, consequently, was placed on projects addressing high risk, preschool-aged children. The review included a close examination of the research literature, on-site visits to highly recommended projects, and extensive interviews with fourteen competent and respected researchers in the field.

The results of the survey were significant because they indicated, rather clearly, that educational programs for preschool, handicapped children—whether they be infants or five-year-olds—*can* significantly improve the quality of the children's lives.

In this chapter, the evidence which supports intervention, as well as certain problems with present intervention programs, will be discussed.

[1] The five were the author, and Dr. Ira Gordon, University of Florida; Dr. Ron Parker, Random House; Dr. Paul Dokecki, George Peabody College; and Dr. Nicholas Anastasiow, University of Indiana. The study was conducted under contract HEWOOS-72-206.

DONALD J. STEDMAN is Associate Director of the Frank Porter Graham Child Development Center and Professor of Education at the University of North Carolina. His professional interests include child development and mental retardation.

IN SUPPORT OF INTERVENTION

The Findings

The results of a close examination of more than forty longitudinal intervention research programs for high risk children included the following major findings:

1. The manner in which a child is reared and the environment into which he is born have a major impact on what he will become.

2. Factors such as race and sex do not appear to be related to the child's ability to profit from intervention programs.

3. The family's methods of establishing social roles leave little doubt that early family environment (parental language styles, attitudes toward achievement, parental involvement and concern for the child) has a significant impact on the child's development before he reaches his second birthday.

4. In situations where families are so disorganized that they cannot supply a supportive environment, an intensive external supportive environment may contribute to the child's development.

5. The effects of a stimulating or depriving environment appear to be most powerful in the early years of childhood when the most rapid growth and development take place. The primary locus of the child during these early years is the home. Therefore, home-based intervention programs or one-to-one teacher-child ratio stimulation activities appear to be the most appropriate and effective during this period.

6. There is evidence that the effects of early intervention programs for children are strengthened by the involvement of the child's parents.

7. It is only possible to describe the training conditions that handicap a child or lead to a child's success in general terms.

8. The socio-economic status and entry level IQ of the child bear an uncertain relationship to the child's ability to profit from intervention. Design problems and the current state of the art in

measurement render the effect of these factors difficult to determine.

9. Where access to children can be gained in the early years, preferably during the language emergent years (one to two years of age), intervention programs will be more effective than those begun at later ages.

10. A systematic organized program can contribute significantly to a child's social and intellectual development between the ages of four and six years.

11. The effects of intervention programs appear to last only so long as the child remains in the intervention program. They appear to last longer in home training studies and "wash out" sooner in school programs.

12. Follow-up studies of children in intervention programs usually show that initial gains are no longer measurable. This is partially attributable to the fact that we cannot determine at this point whether it is due to program failure, to problems of measurement, to inadequate criterion measures, or to the later interfering effects of other competing environments, such as the home and school.

13. The quality and motivation of the staff are directly related to the success of the program and therefore are prime factors in determining the extent to which a program is exportable or replicable.

Successful Intervention

Some findings are worthy of special note since they concern frequently asked but seldom answered questions of importance to researchers and educational practitioners:

In the successful programs, gains occur regardless of age of entry. The starting age of children placed in intervention programs has varied across projects from those starting at a few months of age to a beginning age of five or six years. Results reported by at least one study have shown that children who enter learning-to-learn programs at age four make gains of nearly 20 IQ points which are maintained during the following two years. Children who enter at age five make smaller gains for each of the two years (9 points the first year and 7 points the second year). Although these results suggest differential gains as a function of age of entry, they do not answer the correlated question of whether gains would be sustained after the first year in the absence of such a program.

However, data from another project indicate that children who made gains in the project when they entered did not lose those gains as long as they remained in the program. The data do not strongly support any one year as the more preferred year to realize gains in intellectual growth.

Hence, the general conclusion must be that programs have been effective with all ages and one cannot specifically support the advantages for work at any one year versus another.

Nohe of the studies reviewed gives support to a well defined critical period as a preference for preschool or early childhood intervention. Essentially, programs can be designed that will work effectively with a wide age range.

A comprehensive review of intervention programs in 1970 suggested that vulnerability to adverse influences at certain ages does not necessarily imply a correlated time when children are especially sensitive to treatment. This study supported the contention that, on the basis of our current level of knowledge, intervention can be justified throughout the period of early development and possibly beyond.

In successful programs, gains occur regardless of sex. While studies have reported that girls have higher initial IQs than boys, gains were not related to the sex of the child. These findings are supported in general by other investigators, many of whom do not separate IQ scores by sex when reporting gains because of the lack of differences.

In successful programs, gains occur regardless of race. Studies again report that although whites enter with higher initial IQ scores, race is not a significant variable in considering gain scores.

Differential gains in IQ scores occur as a function of the entering or initial IQ score, the program intensity, and the duration or length of time a child is in the program. In general, the lower the initial IQ, the greater the gain in IQ in the intervention program. Again, the more intense the program, the more likely he is to have a higher IQ gain. Finally, the interaction between intensity of program and duration in program contributes to differential gains. Some researchers, Bronfenbrenner for example, attribute the high initial gains to the phenomenon of *regression to the mean* and characterize the gains as being *inflated* for that reason.

agression

In successful programs, gains occur regardless of program approach *but some programs appear to be better than others.* Although almost all kinds of programs have shown gains in IQ scores, some differences are evident, when specific comparisons are made among programs. In general, it should be stated that some programs work while others do not. In those that are successful, it is apparent that the degree of program structuring is higher than that of unsuccessful programs. In general, the more structure, the greater the gain of IQ in participating children. A large-scale comparison among programs has been conducted by using four groups (regular nursery school, children from low income families in middle class nursery groups, Montessori or perceptual motor skill groups, and an experimental group with a highly structured format). When gain scores on the *Stanford-Binet* were compared, the experimental group (the structured) program was perceived as having the largest gains. It should be mentioned that the experimental group emphasized verbal behavior, a procedure which would tend to influence test scores. Although the remaining three groups may have excelled on other measures, the program of the experimental group resulted in the largest gain on intelligence test scores (IQs).

THE PROBLEMS WITH PRESENT INTERVENTION EFFORTS

A number of serious cautions, which emerge from the review and consideration of research and development activity in this area, involve the scope of present efforts.

1. The sample size of most projects is insufficient for the amount of trust and credibility placed on their outcomes.

2. There is insufficient research in the area to date. After ten years, the number of well-designed and well-executed studies still number less than forty.

3. The majority of studies do not involve the subjects in the intervention program for a sufficient amount of time to allow for long-term change or an adequate test of the intervention program.

4. Insufficient attention is paid to the effects of mixing varieties of children, handicapped and non-handicapped, in order to improve the learning environment in which the intervention program is taking place.

5. The current measures available to assess change in children as a result of intervention program effects are inadequate in number

and quality.

6. The low utility and low reliability of pre-test scores from high risk children (resulting from their meager amount of experience with testing or evaluation approaches) may lead us to infer greater gains from post-test scores than should be inferred as resulting from intervention activities.

7. There is increasing doubt as to the value of certain critical periods; therefore, the extent to which we can continue to emphasize only one period when we can expect positive outcomes of early intervention activities to occur is questionable.

8. There is a typical failure to individualize programs. That is, there is a homogeneity of treatment whether it be social class, IQ level, sex, minority group, or other critical features, across heterogeneous groups.

9. There are often significant cultural differences among minority and ethnic groups leading to differential reactions to intervention programs. This may lead to exaggerated responses from the children in either direction. Also, there are in many cases extreme value differences between subjects and their families and the project staff which may lead to inadequate or inappropriate intervention program components and results.

10. Program goals are often too narrow and constricted. There is more to development than IQ.

11. There are certain gains or responses to the intervention activities which are related to the motivation of the parents to encourage and assist their child in participating in the program. This parental support factor is not often considered as a part of what accounts for intervention programs' success.

12. There are severe logistical problems in connection with both the conduct of longitudinal studies and the development of exportable intervention program components.

13. There is an insufficient number of replications of special studies showing positive or hopeful results.

14. The cost of longitudinal studies has resulted in too few compre-

hensive studies, including health, education, social, and parent program components.

In general, the group concluded that preschool educational intervention programs *do* have important and positive effects on the *IQ* of children. The results are often uneven and transient. There has not yet been sufficient research to warrant the selection of one specific set of program components as being the most contributive to cognitive and social gains.

Special Problems

A number of obstacles in conducting studies appear to be adding to the difficulty of determining the effectiveness and credibility of outcomes.

Inadequate control groups Given the problem of adequately describing the population, it rarely becomes possible to determine the adequacy of the control group. Rarely are children selected from the same population pool and randomly assigned to treatment groups.

Treatment drift Once an evaluation model is adopted, decisions are made to change the program according to information gathered. This is a highly acceptable practice in the remediation of children's deficiencies. As this occurs, however, the intervention program is no longer being conducted as originally described. As a longitudinal study refines its procedures, new strategies are invented; thus the original procedures are markedly changed. Frequently, the change is not described in the write-up.

Press to do well Most innovators are funded to demonstrate the effectiveness of a given idea or program. They are expected to succeed. Given the press to succeed, the program is constantly revised and modified on the basis of pupil responses. In a process similar to that of treatment drift, the program in operation often bears little resemblance to the written proposal.

Teacher effect Evidence indicates that the teacher, not the program, may be the crucial variable in creating change. Indications are that the method or program adopted interacts with the stylistic treatment of the teacher. Teacher factors relating to the change are highly idiosyncratic and difficult to control. One researcher has identified four major clusters of teachers on the basis of control and expressions of warmth. Another researcher has pursued other sets of teacher personality factors that influence pupil change. Yet another has identified planning and supervision as being more important to the program than the curriculum components themselves. How you do something may be more important than what you do.

Teachers reach criterion performance Frequently, a program is developed by an innovator who then hires a staff to conduct the program. In the experience of the author, it frequently take as long as two to three years before the staff can conduct the program as originally conceived. Massive in-service efforts with frequent supervision and evaluation of teacher performance, are needed in all intervention programs. Some personnel will not be able to reach criterion performance and will need to be replaced.

Ethics with human subjects The innovator, in dealing with human subjects, cannot manipulate the research environment unless he is sure he will not damage the child in any way. This ethical "restriction" is necessary in working with human subjects and limits the degree of manipulation the innovator can apply. For example, does one remove children from their mothers in order to work intensively with them?

Continuity of staffing As with life-span research projects, it is difficult for a principal investigator to commit himself over his own life span. If the principal investigator leaves the project, there may be a shift in focus or interest when a new principal investigator takes over. There are also changes in staff training or staff development activities and staff turnover, especially in university-based programs where graduate students are used extensively.

Testing procedures Again, as with life-span research projects, testing schedules, instrument revision, and discontinuity and low correlation between tests brought into the long-term testing activity make conducting the project and interpreting the data difficult.

Data processing Masses of data, which may accumulate in longitudinal studies, can present both problems of data processing and difficulties in decision making as to which data to process. This data accumulation is especially problematic for the new researcher in the intervention field.

Environmental changes Children in longitudinal studies are often influenced by major shifts in the community or neighborhood environment. These shifts may have a direct effect on the outcome of the intervention activities. Shifts in cultural mores, social attitudes, and values may have similar effects.

Attrition The mobility of the American family is well known. While techniques are available to adjust to subject attrition, it is an expensive process and often requires resources not provided in the intervention programs. It is essential that large subject samples be acquired and maintained over a long period of time in order to circumvent the problems caused by subject attrition.

Interpretation

Often, the interpretation of the results of well designed and conducted studies constitutes a major task. The group attempted to examine the nature of interpretation problems and suggested the following points:

Nature of the population In work with high risk youngsters, the set of variables associated is multiple and often incomparable. For example, the construct "culturally deprived," used by different research workers, includes: income level, racial differences, inadequate diet, protein deficiency, punitive child-rearing practices, low language stimulation, isolation, oppression, high disease rates, alcoholism, and so on. It often is assumed that all of these factors contribute the same influence. Clearly, the state of the art—when it comes to knowledge of how to deal effectively with high risk populations—it is not developed to the point at which the population of children can be described with the precision needed to replicate a study. In addition children who live in poverty are still found in markedly different environments—for example, contrast the immigrant worker's child with the child of the inner city dweller or the sharecropper. The life experiences are markedly different.

Problems of program description One of the major problems in interpreting intervention programs is that often the program descriptions are not sufficiently detailed to make clear what it was that the innovator did. Global terms that make it difficult either to replicate or to isolate the variables that were related to the treatment are frequently used. For example, a study of adopted versus non-adopted children may not adequately define the nature of the treatment, i.e., what happened in the homes that did not happen in the orphanages to cause the results. Longitudinal intervention studies rarely describe all of the procedures used in beginning and maintaining a program. It is, in fact, frequently impossible to describe exactly what was done in a program. A major intervention program may have components that deal with classroom experiences, parent training, improved nutrition, medical screening, and vision and hearing tests. Ascribing treatment success to any one variable is a tenuous procedure.

Failure to develop appropriate instruments One of the major difficulties in conducting studies with children is specifying exactly what evaluation the innovator will be able to perform after the intervention. Many programs specify IQ scores as their objective. However, IQ scores are unreliable and invalid for most minority group children and, moreover, IQ refers more to traits related to school performance than to cognitive functioning. The appeal of the behaviorally oriented programs is their tendency to limit their goals to observable behaviors. However, the weakness of this approach is that one is still left with the problem of defining the "internal processes" of the child and, frequently, minor and sometimes irrelevant behaviors.

Global measures of intelligence and achievement are inappropriate measures for program impact. Intelligence measures assume common cultural experiences, equal opportunity to learn, and equal motivation to do well on the tests. For most minority group children, these assumptions cannot be met.

Achievement tests contain many items aimed at reasoning ability rather than at the skill under treatment. For example, as much as fifty percent of elementary school reading tests are inference problems rather than reading problems. Reading is learning a set of abstract arbitrary symbols and relating them to another set of symbols that are spoken—that is speech. Children can relate words to print and learn that the printed word stands for the spoken word or for objects, but unless long trials of memorization, drill, and practice techniques are used, children do not understand the abstraction of graphemics until ten to twelve years of age. Thus, many reading tests are misnamed; they would be more appropriately titled "reading from reading" tests.

Intuitive appeal of gain scores In spite of the work of Cronbach, Thorndike, and others who demonstrated that gain scores are unreliable, statistically indefensible, and subject to great misinterpretation for individuals or groups, there still exists great pressure for programs to demonstrate effectiveness by measuring gains on the same instrument.

Measurement should not concern itself with change as measured by gain scores but with change measured by performance of the desired behavior that defines the criterion performance. Criterion-referenced tests are difficult to construct unless the behaviors are readily observable. For example, it is easier to specify that, as a result of the program, children will be able to count to ten or identify six primary colors than to specify that they will develop a positive self-concept and attitude towards others.

Inadequate or naive theory of human behavior Many longitudinal studies fail to conceptualize the nature of human learning and the processes of development. The results of these studies can easily be misinterpreted. Recent findings in developmental theory and learning have been massive. The human organism is an impressive information processor from the moment of birth. Many, however, still failing to recognize the infant's capacity to process information continue to perceive the child as a passive receptor of information, and thereby attribute to their training procedures more power than is likely to be present. In the same way, the innovator who works with the handicapped child frequently views all that the child lacks in terms of and as a function of his handicap without taking into account his age and the normal stages of growth and development.

Retrospective data, time, and cost Most retrospective data collected from teachers and parents bear little resemblance to the child's actual functioning. The unreliability of these data makes longitudinal studies all the more necessary. However, longitudinal studies take time and careful record keeping. It may be twenty years before the effects of the intervention program can be fully measured. Longitudinal studies are costly ventures, although they may be the only means by which some questions can be answered.

Delayed effects Rarely do longitudinal studies measure delayed effects of their treatment. For example, does the program introduced in kindergarten have any measurable effects on adolescent behavior? Rarely do school programs measure adult attitudes, voting habits, reading habits, or other goals which were part of the school curriculum.

Narrow focus of the program Some longitudinal studies become so specialized and deal with such a narrow population that they cannot be replicated. For example, a program that provides a one-to-one teacher/pupil ratio for six hours a day, six days a week, with supporting psychological, medical, and speech staff would be difficult to find in a regular school.

Sample problems The size of the sample and the representativeness of the sample must be taken into account more seriously. Samples have generally been too small to allow for much generalization. The results of a program that also limits itself to a unique population have little generalizability to other populations of high risk children. Further, shrinkage of already small samples occurs over time and contributes to the lack of follow-up results or effects.

The effect of continued assessment or observation The effects of continuous testing in long-term studies, including observer effects, can have an equal or perhaps greater effect on performance than some or all of the program components. In many programs, continuous assessment and the intervention curriculum are,confounded in such a way as to prevent attribution of responsibility for changes in a child to either assessment or curriculum. In some cases, continuous assessment of control groups may contribute to changes that are equal to changes in the experimental group and thereby make it impossible to measure the effect of the intervention program itself. In some cases, researchers suggest that continuous assessment is equivalent to minimal intervention. Intervention studies are no less immune to the Hawthorne effect than other studies.

SUMMARY

In the final analysis, even given the cautions, design problems, and difficulites with data interpretation, it was felt that we already know a great deal about the effectiveness of educational intervention. In general there are positive effects. A host of factors, including child variables, setting variables, and the characteristics of the intervention program and the people delivering it, operate to make education more or less effective for the individual child.

More research is required, in the field with carefully described curriculum components and the best child variable control possible, within bounds of natural groupings of children. If there is a prime obstacle, it is lack of measurement tools for social, affective, and interpersonal change, as well as for academic gain. Methods of coding and analyzing observational data lag far behind other methods in the social sciences.

Finally, the expensive, long-term, longitudinal study of development in children is still the best strategy for discovering environmental effects. The major difficulty is getting public or private resources to support these operations.

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FACT SHEET

THE ARGUMENT FOR EARLY INTERVENTION

What is meant by early intervention and why is it so important?

Early intervention usually means discovering problems and doing something about them before a child's development and learning are seriously, perhaps permanently, affected. Early help can prevent other deleterious conditions from developing and can lessen concomitant difficulties such as family upheaval or disordered emotional reactions of the child.

Learning specialists believe that skill development is related to both a state of readiness and an opportunity for learning a given skill. Timing of the intervention becomes particularly important when a child runs the risk of missing an opportunity to learn during a state of maximum readiness. If the "teachable moments" or readiness stages are not taken advantage of, a child may have difficulty learning a particular skill at a later time. Langley (1976) stated that the more time that elapses between the period of optimum readiness and the time when the opportunity for learning is provided, the greater the difficulties in learning become. Langley traced the effects of lost teachable moments in the six Piagetian stages of sensorimotor development.

Some types of impairments require particularly prompt attention. Downs (1972) reported that 60% of a child's basic language abilities are established by age 2; therefore deafness must be identified in early infancy in order to use the child's residual hearing during the critical periods for language development.

In an early study, Heber, Dever, and Conry (1968) found that groups of disadvantaged children, particularly children whose mothers had IQ's of 75 or below, showed a steady decline from an estimated normal IQ, measured in infancy, to the level of their mothers by the time they were 3 years old. It is possible that early intervention could halt such a decline.

How reliable are early predictions of intellectual functioning?

The utility of infant intelligence assessment is a matter of debate. Lewis and McGurk (1972) reported findings that "cast serious doubt on the notion that the concept of general intelligence is applicable to the period of infancy. [They] found no evidence to support the view that intelligence is a capacity which unfolds at a steady rate throughout the process of development and which increases only quantitatively from one age to the next." (p. 1178)

The major difficulty with infant tests of intellectual functioning is an apparent bias toward sensorimotor functioning. Meier (1975) pointed out that scores of infant intelligence tests have been more highly related to subsequent sensorimotor performance than to intelligence.

What does research say about the effectiveness of early intervention?

Initial studies (Bronfenbrenner, 1974) raised serious questions about the effects, quality, and costs involved in preschool intervention. Within the past several years, however, research has indicated more positive results. Hayden (1977) found that 34% of preschool handicapped children who had been enrolled in model preschool programs from 1969 to 1976 subsequently attended regular classes and were doing well.

Lazar, Hubbell, Murray, Rosche, and Royce (1977) analyzed data from 12 separate programs serving disadvantaged children in center based, home based, and mixed programs, and found that the experimental group children in almost every program were performing better in school than were control group children from identical backgrounds. That is, fewer experimental group children were in special education and fewer were detained a grade.

In addition, results of a survey of more than 40 longitudinal intervention research programs for high risk children (Stedman, 1977) indicated that educational programs for preschool handicapped children can significantly improve the lives of children.

Most early intervention research has been aimed at the economically and socially disadvantaged population. Barrera and his colleagues (1976) cited the paucity of data with handicapped infants and related their own findings, in which biologically handicapped children made significantly more progress in areas clinically selected for treatment than in areas treated on a random or control basis (Barrera, Routh, Parr, Johnson, Arendshorst, Goolsby, & Shroeder, 1976)

What are some abuses of preschool screening?

When screening is used for prediction rather than for educational planning, abuses can result. Zeitlin (1976) suggested that preschool screening can be a negative force when:

- No followup program is developed
- Initial screening is used as a diagnosis on which to base remediation or placement
- Results are used to exclude children from school by suggesting that they are not ready
- Stigmatizing labels are assigned
- Screening is used to reinforce and justify existing curriculum centered programs
- Results focus on weaknesses alone rather than on strengths
- The effects of cultural differences or bilingualism are not considered

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Prepared by Carol A. Lloyd, Information Specialist
The Council for Exceptional Children

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REACHING HANDICAPPED CHILDREN IN THEIR EARLY YEARS

The information in this fact sheet is taken directly from *Early Childhood Education for Exceptional Children: A Handbook of Ideas and Exemplary Practices*, edited by June B. Jordan, Alice H. Hayden, Merle B. Karnes, and Mary M. Wood.

Why is early intervention important?

There is evidence that programs providing early educational and therapeutic programing to meet the needs of young handicapped children and their families are reducing the number of children who will need intensive or long term help. The importance of reaching handicapped children early and working to help them reach their full potential cannot be overemphasized. With early help, the sooner the better, these children can often function at higher levels than had been dreamed possible in prior years. (p. 3)

What conditions can be identified very early?

For children with certain kinds of handicapping conditions, identification can occur at birth. For instance, children with physical anomalies such as microcephaly or deformities such as cleft palate, children with severe cerebral damage, most Down's syndrome children, and children with extremely low Apgar ratings or very low birth weight are usually identified within the first five minutes following birth. Other indices of handicapping conditions may be noticed during the first few days following birth. Behaviors and characteristics that normal infants do not exhibit such as coma, severe lethargy, constant crying, convulsions, recurrent apnea, bulging fontanelle, rapidly increasing head size, unequal size of eye pupils, absent corneal reflexes, and paralysis of any extremity, facial muscle, or eye muscle serve as indicators that the child is at high risk and needs further extensive assessment. (pp. 68-69)

What conditions may complicate early diagnosis?

Identification, screening, and assessment may be complicated by many factors. The age of the child and severity of the handicapping condition(s) may make accurate assessment difficult; resources and personnel to conduct early screening and assessment may vary widely from one community to another; environmental conditions affecting health and health habits may vary considerably; differences in nutritional intake and eating habits or lack of sufficient nourishment may cause problems; and certain cultural, religious, and language differences pose difficulties in assessment unless those who are screening and assessing are thoroughly acquainted with the populations with whom they are working. Basically, children from backgrounds other than the White middle class should not be classified or labeled with instruments that were standardized on White middle class children. (p. 68)

Many handicapping conditions may go unnoticed for some time. Children suffering from these conditions evidence subtle developmental lags that may not be identified until later in life. Often the parent is the first person to suspect a problem. The fact that parents are often the first to suspect a problem is due to the lack of formal procedures to screen children between the newborn nursery and school and to pediatricians' lack of time or the techniques to notice developmental problems.

Too often the doctor's suggestion that a handicap is probably not serious and should be ignored leads to a delay in providing appropriate services. Even if techniques for screening were routinely used, many young children, especially those from lower socioeconomic families, would not have access to them because they do not receive continuous health care and their problems often go undetected until they enter school. The time span during which handicapping conditions remain undetected needs to be shortened, and formal screening is one method for reducing this time. (p. 69)

How can a screening program help reach more children at risk?

Screening can be defined as the testing of a large population in order to identify those individuals who are most likely to manifest a handicap. It is a formal procedure for identifying people with suspected handicapping conditions. Screening is not—or should not be—used to label an individual, nor is it used to prepare specific objectives for intervention. A more intensive and complete assessment must follow for those individuals identified through the screening process. However, screening is an essential first step, an "early warning" signal that more intensive, precision assessment of a child's strengths and deficits is required in order that remedial—or, ideally, preventive—activities can be initiated.

There are instances of established screening techniques that are in common practice today. One example is the screening of PKU (phenylketonuria), which is mandated by law in many states. This relatively simple procedure of taking a urine sample for analyses during the first few days following birth has proven to be an effective device for identifying children with PKU (pp. 69-70).

Why is it important to involve parents in early intervention?

The involvement of the child's family as an active participant is critical to the success of any intervention program. Without such family involvement, any effect of intervention . . . appears to erode fairly rapidly once the program ends. In contrast, the involvement of the parents as partners in the enterprise provides an ongoing system which can reinforce the effects of the program while it is in operation, and help to sustain them after the program ends. (p. 210).

- Parents of a handicapped child will have more responsibility for their child over a significantly longer period of time than parents of a normal child. They need parenting and teaching skills that parents of a normal child need not necessarily possess.
- Parents usually know their child better than anyone else. Parents can thus serve as a vital resource to program staff in the development of functional program objectives for the child that will be useful in his or her own unique environment.
- Transferring learning from the classroom to the home has been an acknowledged problem. This occurs because there is insufficient and/or ineffective communication between parents and teaching staff. Thus, it is vitally important that there is planned consistency between the educational program and the educational experiences provided by the parents. Without effective parent involvement, the best possible program for the child will have little effect.
- Parent training during the preschool years is beneficial not only for the target child but also for his or her siblings.
- The training of parents, who already are natural reinforcing agents, will provide them with the skills necessary to teach new behaviors effectively and to modify inappropriate behaviors that interfere with learning.
- Parent involvement can greatly accelerate the child's rate of learning. The center, working with the child without benefit of parental involvement, cannot begin to accomplish alone what staff and parents can accomplish together (p. 211).

Where can parents go for help?

Closer Look is a national service for parents of children with mental, physical, and emotional handicaps. This agency offers information about places and people to turn to—organizations, agencies, and offices that can help in locating programs and coping with problems. *Contact:* Closer Look, The National Information Center for the Handicapped, P.O. Box 1492, Washington DC 20013.

Centers where comprehensive treatment, evaluation, and follow-up services for children suspected of mental retardation are listed in *Clinical Programs for Mentally Retarded Children*, 10th edition. Single copies are available free from: Bureau of Community Health Services, Program Services Branch, HSA PHS, 5600 Fishers Lane, Rockville MD 20857.

Crippled Children's Services (CCS) is a joint federal/state program to provide medical and related services to handicapped children from birth to age 21. All states must provide medical diagnoses and evaluation free for all children. No state residency period is required before such services are provided. The range and cost of additional treatment or hospital care services vary from state to state. All programs accept third party payments such as Medicaid, Blue Cross and Blue Shield, and other medical insurance. For further information on what is available to your handicapped child, contact your local county or state health department.

The Early Periodic Screening, Diagnosis and Treatment Program (EPSDT) screens children from poor families to identify whether health care or related services may be necessary. Children receiving state Aid to Families with Dependent Children (AFDC) benefits and children whose parents or guardians are receiving Medicaid and/or local or state public assistance benefits are eligible for EPSDT. EPSDT programs vary from state to state and are administered by either state public assistance (welfare) or health departments. For more information on EPSDT contact your physician, local or state health department, or public assistance office.

To find out about preschool programs for handicapped children contact your local school district or the State Director of Special Education.

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EFFICACY OF EARLY INTERVENTION

FACT SHEET

[redacted]

1. "Fifty percent (50%) of a child's intelligence developes before age 4, eighty percent (80%) of intelligence developes before age 8." (Bloom)
2. "If intellectual development is 80% formed between birth and age 8, the handicapped child will need the most assistance during the early years to develop intellectual abilities which lead to a satisfying life." (Hammer)
3. "Research has shown that there may be critical periods for the development of certain skills, and that most of these periods occur in the first three years of life." (Hayden and McGinness)
4. "With a delay in remediation of an intellectual or cognitive handicap there is a cumulative achievement decrement...apart from the danger of secondary emotional or sensory handicaps, the condition is progressive - the child's developmental status inevitably becomes worse with respect to other children as he grows older." (Jensen)
5. Skeels and Dye (1938) took 2 groups of orphaned institutionalized mentally retarded infants as experimental/controlled groups. The experimental group was given an enriched environment; the control group was left in the ward with little stimulation. By 1942 the experimental group gained an average of 27.5 I.Q. points; the control group lost an average of 26.5 I.Q. points. 1966 follow-up studies:

Control Group:	Experimental Group:
Four still institutionalized	All self supporting
1 dead after long period in institute	Median Grade completed - 12th
Average grade completed-less than third	Average time in insitute - 5 years
Average time in institute - 22.75 years.	More satisfying life in all aspects measured

6. Kirk (1958) - chose 81 children, ages 3-8 year; I.Q. range 45-80. The experimental group received nursery school training; Control group no nursery school.

Follow-up covered several years.

Results: 70% of experimental group gained 10-30 points in I.Q.
Control group I.Q.'s decline.

NOTE: No studies which involved children six years or older were able to equal the gains of Kirk - Skeels.

7. Heber and Garber (1975):

   40 infants with deprived mothers, with I.Q. of 75 or less.

   20 were given all day infant day care to age five.

   20 were left at home.

   Results: Major differences in I.Q. appeared at 18 months and continued to six years.

   Follow-up (1978):

   I.Q.: Experimental group average 100; Control group average 80.

8. "In programs of early intervention, children showed substantial gains in I.Q. and other cognitive measures during the first year of the program, attaining the average or even exceeding the average for their age." (Bronfenbrenner)

9. Lazar's 18 year longitudinal study of 14 yearly intervention programs for disadvantaged children:

   Findings: I.Q.'s increased and then faded by end of third grade, but gains reappeared at 7th and 8th grades. Special education placement and retention decreased for experimental group.

10. "Only 1% of children whose parents had participated in a home-based program needed special education in 5th grade compared to 30% of control group who needed special help in 5th grade." (John Meier - Office of Child Development)

11. Early intervention with deaf children prevents stereotypic behavior (Northcutt,

    "Intervention with deaf youngsters before the age of two resulted in these children's adaptions to normal classrooms whereas deaf children who were not in intervention programs until the age of three did not make these adaptations." (Horton, 1974)

12. "Blind babies must have tactile and auditory stimulation during the first year of life to avoid maladaptive and stereotypic behaviors." (Fraiberg, 1977)

13. "Down's infants enrolled in early intervention programs reached developmental milestones at or near ages for normal children, while Down's children not in programs were delayed from 10 to 40 months on the same milestones. (Hansen)

Cost Benefit: The cost benefit ratio of early intervention usually makes it more economical later. (Hayden and McGinness)

The President's Commission on Mental Health Task Panel on Prevention, February 15, states, "...that major primary prevention efforts must be focused on prenatal, perinatal, infancy, and childhood periods...Top priority for program development, training, and research in primary prevention should be directed towards infants and young children and their environments, including particulary efforts to reduce sources of stress and incapacity and to increase competence and coping of the young."

THE COST EFFECTIVENESS OF SPECIAL EDUCATION

The following studies are illustrative of the long-term cost effectiveness of special education services. They point overwhelmingly to the fact that the earlier intervention takes place, the greater the cost effectiveness in terms of human productivity and community savings.

Recently the cost of providing special intervention at various age levels was calculated (Wood, 1980). The total cost per child to age 18 for four entry ages as follows:

intervention at birth - $37,273
intervention at age two - $37,600
intervention at age six - $46,816
intervention at age six with no eventual movement to regular ed - $53,340.

Thus, the cumulative cost is actually less the earlier the intervention begins.

Schweinhart & Weikart, 1980 found that when schools invest about $3,000 for one year of preschool education for a child they immediately begin to recover their investment through savings in special education services because children with preschool education had fewer years in special education and were retained for fewer years in grades; and an additional $10,798 in projected lifetime earnings for the child.

In another study (Fredericks, Anderson, Baldwin, Grove, Moore & Beard, 1978). 65% of the variance in gains made by two groups of severely handicapped students was attributed to the number of minutes of classroom instruction provided each day.

A recent review of statistics conducted by Rehabilitator International (1981) in cooperation with the United Nations pointed out that "the lifetime earnings of mildly retarded adults is many times the cost of their education - almost a 6:1 adjusted for the percentage employed. Educational services can be therefore justified on the basis of earnings alone."

Braddock (1976) using the concept of educational payback, calculated that income taxes alone generated from gainful employment of a visually impaired person could produce savings for the community of $16,304. If savings from the lack of disability income maintenance were added to this figure, total savings would be $61,144 for each visually handicapped person. Long term savings for speech impaired persons totaled $87,076 and for mildly retarded persons, $441,289.

A U.S. General Accounting Office report cited in Closer Look in 1980 estimated that with vocational training, 75% of physically disabled students and 90% of mentally retarded students are capable, at minimum, of working in a sheltered workshop environment.

From an economic standpoint it has also been proven that alternative community living arrangements are more cost effective than State Hopsital placement. In April 1979, the University of the Pacific, in cooperation with the Valley Mountain Regional Center in Stockton, did some calculations of cost. Their summary of 1979 tax expenditures in one example looks like this:

Total hospitalization cost	$33,771/year/client
Total community cost	13,782/year/client
Total savings based on differences	$19,989/year/client

Even if allowances for more equitable community rates, better trained staff, more stringent standards of enforcement and annual inflation, the total community cost should be approximately $18,000/year/client. But the tax savings are still abundant The above amounts include costs for special education, without which these persons would be unable to remain in the community.

Severe budget cuts would drastically affect services to handicapped children. 20-50% of exceptional students would lose services. Necessary services such as speech therapy, adaptive physical education, transportation, "child find," and evaluation and assessment would be decreased. Personnel would be reduced. Teacher/student ration would increase. Reduction in special education opportunities will eventually mean greater social and taxpayer costs. There is a clear need to increase the level of support for all of the current special education programs.

JUSTIFICATION FOR "EXPANSION MONEY THROUGH EDUCATION FOR INFANT PROGRAMS

1. Recent data from the Ad Hoc Committee on Early Intervention indicates that between all the state agencies (Education, Health, and Developmental Services) we are currently serving 58% of the population requiring services. We are presently serving 21,140 infants in California, however projections based on 3% of live births indicate that there are 36,349 infants in need of services. (Ad Hoc Report p. 27.) This leaves 15,209 infants unserved.

2. At present Education spends approximately 5M to serve 1,599 infants. 1M comes from the local general fund, 2M from the state IPSU allocations and 2.1M from the PL 94.142 Infant Discretionary Funds (information from telephone survey conducted Fall, 1983). This amounts to approximately $3,000 per child.

3. Ad Hoc Committee recommendations indicate that all agencies need to expand their programs while developing an interagency service delivery system. (Ad Hoc Report, p. 28)

4. Research indicates that early intervention from birth can save $16,000 per child over the course of his/her education. (Ad Hoc Report, p.10) Given the figure of $3,000 per child currently spent in Education, an increase of 12M would allow services for an additional 4,000 - 5,000 unserved infants (only one-third of those which are currently unserved, see #1 above). Therefore, at a cost of 12M, initially the state would save 64M - 80M over the child's educational years.

EXCEPTIONAL CHILDREN'S FOUNDATION
Fran Chasen
Early Childhood Specialist
Director, Infant Development Program
2226 West Adams Boulevard
Los Angeles, California 90018 • (213) 736-1424

Real Work for Real Pay

WITH THE RIGHT TRAINING, MENTALLY RETARDED ADULTS CAN WORK TOWARD INDEPENDENCE.

BY BEVERLY MCLEOD

One of the unspoken fears of expectant parents is the possibility that their child will have mental retardation. For most, such worries are unfounded. Yet a small but significant percent must face the fact that their child, indeed, will never develop as normal children do.

When a child has an IQ of 70 or below—the point at which people are considered mentally retarded—parents must abandon many dreams and adjust to their child's severely limited prospects. But how limited must such a life be? Must their child live forever in an institution or, if at home, be permanently dependent on the family or the state?

Until quite recently, the answer seemed to be "yes." As Lou Brown, a special educator at the University of Wisconsin, has observed, people with mental retardation "have been devalued, undertaught, their life spaces have been tragically constricted and many negative generalizations have become embedded in the minds and hearts of millions."

Consider, for example, the case of "David Nettleman" (all names of people with mental handicaps are pseudonyms), a teenager with mental retardation. His parents, like many others, were told that he would "always be a child," and he was treated accordingly. Even as a 6-foot, 245-pound young man at a special school, he was never asked to do more than string beads. But today he is receiving on-the-job training at a bowling alley, and he has learned to do

Using the building restroom, an EAS worker learns steps to good grooming.

home chores that may help him get the janitorial job he wants.

Or consider the story of Michael Ortega, a young man with moderate retardation who had spent more than 20 years in an institution. His typical occupation was rubbing his face and staring at his hands. Not a likely prospect to be working steadily for six years and earning $6 an hour training dishwashers, as he now does.

These accomplishments have happened in part because during the past decade attitudes toward the abilities of people with mental retardation have changed—quietly but profoundly. In fact, the Association for Retarded Citizens now estimates that, given appropriate training, 75 percent of children with mental retardation could be completely self-supporting as adults, and another 10 to 15 percent could be partially self-supporting.

The appropriate training, many experts now say, involves enhancing real-world coping skills through meticulous behavioral analysis and modification. The techniques are relatively old, but the determination to apply them to provide greater opportunities for people with mental retardation to become self-supporting is rather new.

Many factors underlie this change, including greater advocacy and recognition of the rights and dignity of all handicapped people. But for those with mental retardation, one key factor has been the widespread influence of a successful employment-training model developed by G. Thomas Bellamy at the University of Oregon about a decade ago. The Oregon program showed that people with severe mental retardation could acquire the skills needed for productive work. That experiment and others that followed raised expectations, first among a few researchers, then throughout the mental-retardation field. As Robert W. Flexer of Kent State University and Andrew S. Martin of United Marketing Services in Lubbock, Texas, describe the change, "... instead of saying, 'These people ... cannot learn and cannot be trained,' we are now saying, 'We have not been competent enough to teach.' The failing is not with the severely handicapped, but with us."

The Oregon experiment sparked the development of many similar training programs across the country. One of the newest is Electronics Assembly Services (EAS), in Alexandria, Virginia, which exemplifies the new approach.

Shortly after 9 a.m., Donna Hodges wheels herself into EAS to begin her job of assembling and bagging circuit boards. She cannot count, so as she finishes each board, she places it next to one of the five black circles on her desk. When all five boards are filled, she puts them in a bag and starts over again. She earns a quarter for every 30 completed boards and is saving her money to buy a blouse held on layaway in the shop downstairs.

Soon the other 11 EAS employees walk in and begin their various tasks. When greeted by Anne O'Bryan, general manager of EAS, they look in her direction but say nothing; most cannot talk. She and her two assistants circulate constantly among the employees, praising and paying them for completed tasks, guiding and helping them if necessary.

O'Bryan takes Ali Mehrabian to a corner of the room and guides his hands during a training session in cutting, stripping and soldering wires. Another staff member accompanies William Jackson to the restroom for a training session in its use. He evaluates Jackson's progress on a chart listing several dozen minute steps to be followed.

Meanwhile, Robert Antonelli begins to growl. One of the staff members immediately makes him stand facing a corner of the room, sets a kitchen timer for one minute and makes a note on his chart. After a minute of silence, Antonelli is returned to his seat. Twenty minutes later, when he begins growling again, the procedure is repeated.

Antonelli, who had lived in an institution for most of his life, had spent the better part of his waking hours growling. During his first month at EAS, he growled an average of 450 times a day. By giving Antonelli a sip of his favorite coffee whenever he was silent for a few minutes and by standing him in the corner whenever he growled, O'Bryan limited him to 300 growls on the first treatment day, 150 on the second and 100 on the third. By the second week's end, his growling had practically ceased. But during a recent hospital stay his usual good behavior had slipped a little.

At noon, some employees eat bag lunches or buy food from a vending machine; others order lunch at a nearby fast-food restaurant by holding up picture cards showing hamburgers, french fries and soft drinks. Hodges collects her quarters and pays another installment on her blouse.

The city of Alexandria hired O'Bryan to set up an employment program for its severely retarded adults. "We don't have a minimum IQ requirement here," she says. "We have a maximum. None of the employees has an IQ above 35, and many of them had lived in institutions for years."

At first it was chaotic, she recalls. The staff members kept popcorn in their work aprons, ready to pop into anyone's mouth who was quiet for even a few seconds. But within only four months, most of the employees had become quiet and productive, and they are now, only a few months later, doing increasingly complex tasks.

EAS represents one of two new approaches to providing job training and employment to adults with severe mental retardation. Like other "supported employment" programs, it provides whatever ongoing support is necessary to enable people with mental retardation to find and keep jobs. Some programs, like EAS, employ a small group of people with mental retardation who do subcontract work for larger companies. In other programs, a group of separately supervised employees works together at a larger company. "Competitive employment" programs provide transitional training and short-term support to prepare people for independent employment, then place them in regular jobs that pay a minimum wage or better.

Many competitive employment programs dispense with standardized tests to determine skill levels for specific tasks. Because such tests, designed for the physically handicapped, do not accurately predict job success for people with mental retardation, clients are often placed directly in the actual job situation, then assessed as the training proceeds. "This is a significant departure from traditional placement approaches, which require the client to be quite 'job ready,'" says Paul Wehman, director of the Virginia Commonwealth University Rehabilitation Research and Training Center. "And it has been crucial to making our track record successful with clients traditionally excluded from services."

INSTEAD OF SAYING, 'THESE PEOPLE CAN'T LEARN,' WE NOW SAY, 'WE HAVEN'T BEEN COMPETENT TO TEACH.' THE FAULT IS NOT WITH THE SEVERELY HANDICAPPED, BUT WITH US.

Many of the new employment-training programs rely heavily on the techniques of behavior analysis and modification. Trainers analyze in detail how nonhandicapped people perform a job, then teach their trainees to follow the same procedures.

When Susan Jameson went to work in a beauty salon, her trainer broke down the job of collecting and washing towels into 85 steps, drying them into another 32 and folding and putting them away into another 100. Training was initially very intense, but Jameson now works on her own with only an occasional visit from her trainer.

Like many other people with mental retardation, Jameson also needed to learn social skills, such as smiling and greeting her coworkers. People who have lived in institutions often do not learn how to interact with others or to care for themselves in socially acceptable ways.

Developing these skills was an important part of a University of Washington program that trained people with moderate to severe mental retardation to work in three on-campus restaurants. Most of the trainees could not read, write, tell time, use money or ride the city bus, and many had poor grooming habits. Special educator Jo-Ann Sowers and her colleagues at the university devised a set of picture cards showing clean hands, combed hair, neat clothing and brushed teeth to teach proper grooming habits. Another set of cards showed two clocks and a lunchbox. One clock showed trainees when to go to lunch and the other showed when to return to work. By matching the cards to a wall clock, trainees were able to keep to the work schedule even though they couldn't tell time.

Similar "shortcuts" are used at EAS. Hodges, for example, uses the five black circles on her desk to help her "count," and employees can buy Big Macs with their picture cards even if they can't say the words. Instead of spending hours painfully trying to write, clients can use a name stamp to cash their paychecks.

How successful are these employment-training programs? Though many are new, they promise greater success than traditional sheltered workshops or activity centers in placing people in the conventional work force—and at higher earning levels.

Federally funded in the 1960s, sheltered workshops were intended as transitional training centers to help

Assembling electronic cables at EAS on contract to Hewlett-Packard Co.

MUTE WORKERS BUY BIG MACS WITH PICTURE CARDS; THOSE WHO DON'T WRITE SIGN THEIR CHECKS WITH NAME STAMPS.

trainees move into the job market. But only about 10 percent of sheltered-workshop clients are placed in competitive jobs each year, and few have severe retardation.

Other programs, called "activity centers," usually serve people with IQ's below 50—traditionally seen as too severely disabled for competitive work and ineligible for vocational training.

Such day programs were expanded by 600 percent between 1972 and 1979, partly due to deinstitutionalization, and now they are serving more than 100,000 people. Not surprisingly, very few clients move on to higher-level vocational programs.

In contrast, competitive employment programs, which serve a similar clientele, have done much better. In three projects supervised by R. Timm Vogelsberg, a special educator at the University of Vermont, clients had been classified as "mentally retarded, severely disabled and unemployable" by traditional vocational rehabilitation services. Despite these dire labels, in a five-year period, 70 percent of those placed were still on the job.

In a similar time span, Wehman and his colleagues have placed 145 people in competitive employment, which Wehman defines as "working for at least a minimum wage with nonhandicapped workers and with no subsidized wage in any way." These people, with a median IQ of 48, were also considered unemployable by traditional rehabilitative services. But they are now working in hospital laundry rooms, medical-equipment manufacturing facilities and food-service settings. They have been on the job for an average of 15½ months, compared to less than five months for their nonhandicapped counterparts.

The earnings of trainees in the newer programs are equally impressive and have potentially profound economic consequences. Sheltered-workshop employees earn an average of only 80 cents an hour, or little more than $400 per year. Activity centers, licensed to serve only "inconsequential producers," by law cannot pay their clients more than 25 percent of the minimum wage. Some states do not allow activity-center clients to earn any money, and even in those that do, "work for pay is viewed as primarily therapeutic, rather than as a means of support," according to Flexer and Martin. The Department of Labor estimates that clients in such centers earn an average of 33 cents an hour, or $160 per year.

The employees of the Olympus program in Seattle, all of whom have severe mental retardation, earn more than $100 monthly. Started in 1977 as a community replication of the University of Oregon's Specialized Training Program (the model for EAS as well), Olympus does electronics assembly work for several firms. Because of employees' earnings, the state was able

Goal in sight: An EAS trainee buys on layaway in a nearby shop.

to reduce their support from a daily average of $22.50 per person to less than $10.

Money is a big issue for these employment programs. Federal and state governments will spend more than $14 billion this year on services to people with mental retardation, primarily to those with severe impairments in institutions. A substantial amount of Supplemental Social Security Income (SSI) payments goes specifically to unemployed workers who are mentally retarded. In all, 8 percent of our gross national product is spent on disability programs. Many experts in the mental-retardation field believe that these enormous costs are likely to skyrocket unless policies affecting the employment of people with mental retardation change significantly.

Mental retardation is a problem that will not go away soon. One in 10 Americans has a mentally retarded family member, and the rate in the United States—3 percent of the population—(6 million Americans)—is rising.

As the public burden of supporting adults with mental retardation grows, so do the economic benefits of the new programs. Intensive, individualized and ongoing training tends to be expensive. But advocates contend that it is less expensive in the long run than total public support. A review of six supported employment programs in Oregon and Washington found that they cost 20 percent less than traditional day-activity programs.

Training costs in the newer employment programs range from $2,500 to $7,500, but that is a one-time cost, after which most trainees become at least partially self-supporting. The 145 clients of Wehman's competitive employment program have earned more than $900,000 during a recent five-year period and have paid $126,684 in taxes. The average employee earned $4,500 per year—almost equaling the public cost of maintaining a person in an activity center.

The cost of training is recouped in four years, and during a lifetime a worker will earn more than $10 for every dollar spent in training. That person will also contribute $530 yearly in taxes.

Despite the many arguments favoring widespread adoption of the newer employment-training programs, there are many obstacles, not the least of which is the welfare system. Many Social Security eligibility rules actually prohibit work and thus discourage recipients from taking a chance on employment training. Such disincentives force people who should have partial support to be either completely self-supporting or completely dependent.

Recent changes in federal law now allow severely disabled people to do paid work without fear of losing their SSI payments and Medicaid eligibility. But even with these changes, many more are needed. Reforming the welfare system is such an overwhelming task that some experts prefer working around it. Special educator Brown even advocates the controversial step of allowing people with mental retardation to work for nonmonetary payment—or even for free—when in danger of being trapped by the Catch-22 of federal eligibility rules. He believes that for employees, the unfairness of this approach is outweighed by the benefits of participating in a normal working life. The public at large benefits, too, by knowing that disability payment recipients "are at least trying to give something in return."

Some researchers and activists are focusing their efforts on state-level reform. Because a pioneering program at the University of Washington showed that adults with moderate mental retardation could succeed in competitive employment, the state of Washington has now made it public policy to support employment programs for people with mental retardation. State funding policies were changed in 1982 to allow community colleges and other agencies to compete for training funds previously restricted to conventional centers, which had little interest in moving people out. "That one change in state law has had more impact on adults with mental retardation than anything else we could have done," says James Moss, employment-training program director at the University of Washington. "It broke a monopoly that profited more from keeping people on the welfare rolls than in getting them off. If this were to happen nationwide, the impact would be phenomenal."

Efforts to provide better job training and work placement for adults with mental retardation have a counterpart in the sphere of public education. Since 1975, children with handicaps have been entitled to free public education. The first wave, nearly 100,000 strong, is now finishing school at age 21 to face an adult service system that provides few options. But some school districts are beginning to develop programs to ready such students for the workplace.

In Madison, Wisconsin, a transition teacher and several vocational teachers work closely with community agencies to provide training, placement and follow-up services for students with mental retardation. Before the program started, only 1 of the district's 53 graduates with severe handicaps worked in a nonsheltered environment. Since it began in 1979, 47 of 61 graduates have found jobs in the community. The program saves taxpayers more than $3,000 yearly for every person working in a regular job.

But this program is still an exception. Most school programs concentrate on teaching the alphabet, rote learning and working on puzzles instead of on developing good work habits and attitudes, according to Paul Bates, special educator at Southern Illinois University at Carbondale.

IN A LIFETIME, A WORKER WITH MENTAL RETARDATION CAN EARN MORE THAN $10 FOR EVERY DOLLAR OF TRAINING.

Three schools in Montgomery County, Maryland, are providing the kinds of functional training essential for independence. Students with mental retardation spend about half of each school day learning how to ride public buses, shop for food and cook lunch at classmates' houses. They also attend school with nonhandicapped students their own age. One student, Joyce O'Malley, while living in a private residential school with autistic and mentally retarded children, had hardly spoken a word. Now she sings in the school choir, gossips with her friends and works in a movie theater after school.

The "behavior problems" seen in youngsters with mental retardation in segregated schools often improve dramatically when they are surrounded by models of normal behavior. Jack Hanson's parents and teachers had tried unsuccessfully for 17 years to get him to stop drooling. But when his boss at a fast-food restaurant told him that he would have to shape up or be fired, Hanson stopped drooling in no time.

Good school programs such as these may supplant intensive job training for many adults with mental retardation in the future. They will also help nonhandicapped youngsters learn more about people with mental retardation. Special educator Brown says, "The best way for [all kinds of people to learn] to function effectively with people with severe handicaps is to grow up and attend school with them."

Such experience is even more crucial for those nonhandicapped students who will one day have children with mental retardation, says Brown. In his view, they may be better prepared than many parents today who are "30 to 35 years old and have never seen a person with a severe handicap except on a poster or a telethon."

Special educator Frank Rusch, of the University of Illinois, is counting on today's parents to push for adequate programs for their children with handicaps. "Parents have always been the greatest reformers in this country," he says. "They should find out what kind of vocational program their schools plan for their children, and make sure that . . . the education process results in meaningful employment upon graduation."

The innovative training programs described here, both for adults and for youth, make up only a tiny fraction of those available. But they provide a powerful demonstration that, with help, even people with severe handicaps can move from the welfare rolls to the employment rolls. The next step, in the view of advocates for this "last minority," is to see that in the future, such programs are in the majority. Both humane and economic considerations argue in their favor.

"Before the introduction of substantial welfare [benefits], it was questionable whether this society could afford to train mentally retarded people for employment," says educator Sowers. "Today it is clear that society cannot afford not to provide such training." ◻

Beverly McLeod is a freelance science writer in Santa Clara, California.

For Further Information

For free information on mental retardation and research programs, write or call:

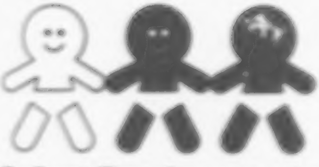
Office of Research Reporting
National Institute of Child Health
and Human Development
Building 31 Room 2A32
9000 Rockville Pike
Bethesda, Maryland 20892
(301) 496-5133

For information on supported employment programs, write to:

G. Thomas Bellamy
135 College of Education
University of Oregon
Eugene, Oregon 97403

SERVICES FOR INFANTS WITH SPECIAL NEEDS IN CALIFORNIA:

OVERVIEW AND RECOMMENDATIONS



Infant Development Association
[illegible] Martin Luther King, Jr. Boulevard, Los Angeles, California [illegible]
MARCH, 1983

FOREWORD

Purpose of Report

This report is intended as an introduction for professionals, parents and other decision makers. It describes the many infants in California whose special developmental needs warrant early intervention services. It describes principles, organization and problems common to several hundred, very diverse infant development programs in the state.

This report also is intended as a strong statement. It documents our knowledge of and belief in the value of infant development programs. It identifies the problems of funding and coordination which limit the preventative potential of early intervention in California.

Authors of Report

The report is based in large part upon "A Report: Task Force on Funding and Quality Standards For Infant Development". This report was prepared in 1977 by seven directors of Bay Area infant programs. The state is indebted to these seven people for their commitment and clear statements which still hold true more than five years later.

The Task Force Report was reviewed by hundreds of people involved with early intervention programs around the state in 1982, updating those areas in which our knowledge has grown. Through the Northern California Infant Network and the statewide Infant Development Association, contributions to this report have been made by those working with infants and families in programs in private, non-profit agencies, hospitals, public schools, universities and child care programs. These programs serve the diverse population and cultures of California, urban and rural, rich and poor educated and not. General consensus from so many diverse programs identifies, in the following pages, what is really essential to helping the infant with special developmental needs attain full human potential.

Copies of this report are available at cost by contacting the Infant Development Association at 3750 W. Martin Luther King Boulevard, Los Angeles, California 90008, (213)290-2000.

Fran Chasen

Nancy Sweet
Nancy Sweet

Infant Development Association

INTRODUCTION

Historical Perspective

Within the last 15 years in California, infancy has been recognized as a critical time for the treatment and prevention of handicapping conditions. Unique community programs have been created to enhance the developmental outcomes for babies with developmental disabilities, or who are at high risk because of medical problems (such as prematurity) or environmental problems (such as child neglect). Known as infant development or early intervention programs, these services have taken different shapes in different settings. Though they differ in many ways, infant development programs share a common purpose: to help the baby with special needs attain full developmental potential, and to aid the baby's family in accepting, caring for and teaching the special baby.

Concern for the developmentally disabled and at risk infant comes from many different perspectives, professionals and agencies. As a result, infant development programs in California may be found in a variety of private non-profit community agencies, in public schools, in hospitals, in child care settings, in parent sponsored organizations, and so forth. Responsibility for services to infants currently cuts across a number of major state agencies in California (Health and Human Services, Education, Developmental Services). In many communities and for certain types of special developmental needs there are no services yet available. There is growing awareness of the need for a statewide plan and approach which assures the availability of appropriate services for infants with special developmental needs and their families. Many other states already have state plans and comprehensive service systems for this population. We believe that infants with special needs in California also have a right to services.

Evidence of Effectiveness of Early Intervention

A growing body of evidence supports the benefits of early intervention for children with special developmental needs. Although initial costs of these programs are high, they result in long-term gains to society, both in dollars and in human potential.

Weikart (1980) calculated a 248 percent return on the cost of two years of preschool in reduced special education costs and increased liftime projected earnings. A study by Wood (1981) found that the costs of education for handicapped children increase as early intervention is delayed. She found sustantial cost savings when intervention begins at least by age two, and maximum savings when intervention begins at birth.

Savings of human potential are even more significant than dollar savings. Many children can achieve higher levels of academic and social functioning and some who would have required intensive special education are able to progress in regular classrooms with little special assistance. Many of the children benefitting from early education programs have been found better able to go on to be happy and productive members of their family and society, instead of being relegated to institutions as they were just a few decades ago.

The benefits to society of early intervention are not limited to increased academic potential of the infant with special needs. As the Comptroller General's Report (1979) stated: "The costs of preventable infant mortality, mental retardation, handicaps, child abuse, emotional handicaps, and lost human potential cannot be measured in dollars... We believe effective early childhood and family development programs can reduce those problems" (pg. 79).

These and other studies of the efficacy of early intervention have been reviewed in several recent publications. These include:

1. Early Intervention For Children With Special Needs and Their Families: Findings and Recommendations, 1981. A monograph prepared by INTER-ACT, The National Committee for Services to Very Young Children With Special Needs and Their Families. Available from the Technical Assistance Development System (TADS) 500 NCNB Plaza, Chapel Hill, North Carolina, 27514.
2. The Efficacy and Cost Effectiveness of Early Education for Handicapped Infants and Preschool Children, 1982. Available from the California Department of Education, Office of Special Education, 721 Capitol Mall, Sacramento, California, 95814.

3. Benefits of Early Intervention for Special Children, 1982, by Pamela Bailey and Pascal Trohanis. Available from the Technical Assistance Development System (TADS) 500 NCNB Plaza, Chapel Hill, North Carolina, 27514.

4. Infants Born At Risk, Tiffany M. Fields, et al (Eds.) New York: Spectrum Publications, 1979.

5. Policy Considerations Related To Early Childhood Special Education, 1982, by Barbara Smith. An ERIC Exceptional Child Education Report. Council for Exceptional Children, 1920 Association Drive, Reston Virginia, 22091.

Evidence of the Need For Early Intervention Services In California

Four recent surveys and studies document the unmet needs of the special infant population in California. The first comprehensive statewide survey of programs serving infants with special developmental needs was completed for the State Council on Developmental Disabilities in October, 1981. This survey identified 190 programs which were providing developmental/educational intervention for 6000 predominately disabled or handicapped infants and 99 programs which provided developmental assessment and follow-up services for predominately at-risk infants.

The Developmental Disabilities Council survey concluded that:

1. "Providing services to developmentally at risk and delayed infants is a complex endeavor requiring the involvement of medical, developmental, educational and psychosocial professionals".

2. "A general model for proving infant development services is shared by a majority of programs serving these infants".

3. "A majority of programs indicated that funding was usually inadequate both in amount and in duration".

4. "If services are to be sustained and improved,the issues of funding, interagency coordination of services, transportation, physician referral, and parental acknowledgement of their infant's problems must be addressed".

A second statewide survey was completed recently for the California Department of Education of handicapped infants and preschoolers being served by public school programs. In addition to analyzing types, costs and availability of special education services, this survey attempted to project the size of the unserved population in need of such services. It concluded that only a small fraction of infants in need of services were receiving them.

A third survey was completed on behalf of the Northern California Infant Network in September, 1982. Using a conservative estimate of 2% of the infant population as developmentally disabled or at risk for developmental disabilities (by school age an estimated 10% require special education), this survey found that at best only 40% and more likely only 20% of that 2% were receiving early intervention services. The survey also discovered that services were fragmented and isolated, and that even a list of early intervention programs did not exist.

A fourth relevant study is a report prepared in June 1982 by Maternal and Child Health on the High Risk Infant Follow-up Project. This report summarized results from nine model programs which provided home intervention for high risk newborns leaving Intensive Care Nurseries between 1978 and 1981. The report concludes that home intervention can result in a savings in hospital costs per baby of $2,118. A second conclusion is that home intervention is a "valuable service in providing medical, emotional and educational support to the high risk infants and their families, which in turn, promotes an atmosphere where the infant can develop to his maximum potential. Incidents of child abuse, neglect and improper care are greatly reduced...". The report recommends expansion of home intervention services statewide to an estimated 10,000 high risk infants.

In summary, each of the four most recent surveys or reports on services to infants with special needs indicates:

1) there are a significant number of developmentally disabled and at risk infants whose needs are not being met;

2) additional funding is needed to serve those infants appropriately;

3) better coordination of services to this infant population is also needed.

Survey References

A Statewide Survey of California Programs Serving Infants With Developmental Needs, October, 1981, Richard Weisbrod, Reseach Consultant. State Council on Developmental Disabilities, 1600 9th Street, Sacramento, Ca. 95814.

Early Intervention - A Working Paper: Baseline Information on Early Intervention Programs in the California Public School System, 1981. Available from Planning Associates, 2011 Carol Street, Suite 4, P.O. Box 549, Merced, Ca. 95341.

A Resource Directory of Early Intervention Programs in Northern California, 1982. Prepared on behalf of the Northern California Infant Network by Nancy Sweet and Diane Lazzari. Available from the authors at the Child Development Center, Children's Hospital Medical Center, 51st and Grove Streets, Oakland, Ca. 94609.

A Report To the Legislature, High Risk Infant Follow-Up Project: Recommendations For Home Intervention Services For High Risk Infants and Their Families in California. Maternal and Child Health Branch, Health and Welfare Agency, June, 1982.

INFANT POPULATION SERVED

Who Is the Infant With Special Developmental Needs?

In simplest terms, three categories of infants can be identified as having special developmental needs, though these groups frequently overlap.

1) the developmentally disabled, delayed or handicapped infant. These infants are the primary recipients of early intervention services. These are infants with identified congenital disorders, sensory or motor impairments, neurological dysfunctions or significant delays in one or more major aspects of development (cognitive, language, social-emotional, gross and fine motor development, adaptive self-help). Atypical developmental patterns create special needs which may continue through out the children's lifetime, requiring special education and community support.

2) the medically or biologically at risk infant. This is the infant for whom early health factors are known to be a potential threat to developmental outcome. The significantly premature or otherwise chronically hospitalized newborn is the most frequently found medically at risk baby, though other medical problems can also result in impaired developmental outcomes. While many of these babies have a higher risk of subsequent developmental problems, the majority have the potential for normal development.

3) the environmentally at-risk infant. This is the infant for whom the postnatal environment, and specifically a dysfunctional parent-infant relationship, threatens the infant's developmental outcome. Environmental risks may include child abuse, child neglect or an inability to provide the nurturance which an infant needs to attain optimal development.

Eligibility For Early Intervention Services In California

Eligibility criteria constitute a key concern for infants with special needs. Different state sources of funding impose different eligibility criteria on early intervention programs. As a result, an infant eligible for services in one area may not be eligible for the services which exist in another. A second result is that certain types of infants, even with known handicapping conditions, cannot be served in some areas.

According to the statewide survey completed by the Developmental Disablities Council cited earlier, the majority of intervention services for infants with special needs are funded through the Regional Center system and the state Department of Developmental Disabilities. Eligibility is based on meeting the state definition of a developmental disability, though some Regional Centers are funding services in a high risk category.

A second major provider of services to the developmentally disabled or handicapped infant is special education. Special education for children under age 3 is permissive rather than mandatory under California's State Master Plan For Special Education. Where infant programs are found in public schools eligibility is determined by "intensive educational needs". Specific eligibility criteria for infants and preschoolers under four years, nine months to receive special education have been implemented recently by the Department of Education.

Other services for infants with special needs are available through the health department. These include the High Risk Infant Follow-Up Projects, referred to earlier, which have specific eligibility criteria. Other services are available to CCS eligible infants, including both handicapped and "normal high risk" infants who meet relevant eligibility criteria.

Still other eligibility criteria exist for handicapped and environmentally at risk children who receive childcare/child development programs through the Office of Child Development in the Department of Education. Private charitable organizations provide services to yet other groups of infants with special needs applying other specific sets of eligibility criteria.

Gaps in services and chronic funding problems result from these different eligibility criteria and service delivery systems. These are two major current problems in services to infants with special needs. A third major problem is also related to eligibility criteria and funding mechanism: services are not adequately preventive. Special education services and many Regional Center funded programs cannot admit a baby unless and until clear handicapping conditions are diagnosed. The at risk category is generally available currently for services only for infants who are ICN graduates. Many infants with emerging delays and a variety of other risk factors which are likely to result in delays are ineligible for services when services might prevent some of these problems. Diagnoses and the extent of handicapping conditions may not be certain during the first years of life, so greater flexibility of eligibility criteria are needed than in later years.

PHILOSOPHY AND STRUCTURE OF INFANT DEVELOPMENT PROGRAMS

Although there are differences among early intervention programs, a basic philosophy and model distinguish these programs from other services for young children and families. The common components of early intervention for infants with special needs are as follows:

1. Infant intervention programs provide assessment and treatment designed to enhance the developmental progress of the infant with special needs.

2. Infant intervention focuses on the individual needs and strengths of the infant, and on every factor which influences those needs and strengths, including health, physical environment, family relationships and so forth.

3. Infant intervention programs modify the environment and experiences of the infant in order to match the infant's developmental stage and then promote progress to the next developmental stage.

4. Infant intervention programs make active efforts to involve the parent in planning and providing the developmental program for the infant. Most are family-centered rather than child-centered.

5. Infant intervention programs provide emotional support, guidance, information and counseling to the parents in order to enhance their resources for caring for an infant with special needs within the family context.

6. Infant intervention programs generally provide a combination of home and center-based services flexibly selected to meet the needs of infant and family.

7. Infant intervention staffing and services are generally multidisciplinary and frequently transdisciplinary, combining education, health and psychosocial expertise and services.

8. Infant intervention programs rely on staff who are infant specialists, with expertise in normal and atypical infant development, and in work with families.

9. Infant intervention programs are usually small (10-50 families) and reflective of their community's composition and needs.

While there are different service components and approaches within this general model, basic and minimum requirements for high quality infant development programs can be identified:

I. Staffing

A. Structure and Qualifications

1. Staff should be infant development specialists, with expertise in normal and atypical child development, appropriate intervention techniques, work with families, and relevant community resources. This expertise is obtained from higher education, inservice training and/or working experience with the birth to three year population. These competencies have been described recently in a monograph: Basic Competencies for Personnel In Early Intervention Programs: Guidelines for Development. Prepared by INTER-ACT, The National Committee for Services to Very Young Children With Special Needs and Their Families. Available from TADS, 500 NCNB Plaza, Chapel Hill, North Carolina, 27514.

2. Staffing should be multidisciplinary, combining essential developmental, psychosocial and health professionals and services (either on staff or through active coordination with other agencies or professionals). The variety and balance represented by these major categories is important. Available professionals should include: a) pediatrician ard other physician specialists as indicated; b) public health nurse; c) psychologist; d) speech and language therapist; e) developmental or educational specialist; f) physical therapist; g) occupational therapist; h) social worker; j) nutritionist. Not all of these need to be on staff but all should be available at least on a consultant or referral basis.

3. Staffing should be transdisciplinary, using a team approach in assessment, program planning and review, and service implementation. Since many families of infants with special needs suffer from fragmented, sometimes duplicated services, multiple professionals and agency involvements, and conflicting advice, one staff member should be identified as the primary and consistent intervenor, if at all possible. The primary staff person then incorporates the skills and ongoing recommendations contributed by each team member into the individual infant's program.

4) The parent must be enabled to be an active, participating team member. Studies of the efficacy of early intervention show that programs are most effective when the parent is an active participant in the planning and implementation of a developmental program for their infant. Parents and family are the primary developmental influence during the infancy period. Parents are the best source of information about their baby. The observations, values, needs and role of the parent are essential team contributions.

B. Staff Functions

1. Initial and ongoing evaluations of each infant should include appropriate assessments by the developmental, psychosocial and health team members. When appropriate, the infant should be seen by the team together rather than by each member separately. Staff must be sensitive to the optimal assessment process for each infant and parent.

2. An initial and ongoing program plan (IPP) should be developed by the team for each infant, with the parent(s) participation. The plan should include general developmental goals for the infant and needed services for the infant and family. Parent(s) should get copies of written assessments, reports and plans. Formal and informal staff and parent-staff conferences should be scheduled to keep the IPP up to date.

C. Other Staffing Considerations

1. The staff should reflect (but not be limited to) the ethnic composition of the community it serves.

2. Ongoing inservice training, continuing education and staff support should be available to staff to maintain professional competencies and effectiveness.

II. Service Delivery System

1. Most effective infant development programs will include both home and center based components. Home programs are essential services during the infancy period since they provide individualized time with each infant and family. Home programs deal with the infant and family in their own environment, and reach out to all families. Center program components can be equally valuable in opportunities for interactions with infants and families and program staff. Group programs often offer opportunities for formal and informal parent-to-parent support, which can supplement and complement staff-to-parent support.

2. In home and center service components, a family rather than child-centered approach is needed. The whole family is part of the infant's learning environment and should be recognized as such in the infant's program plan.

A. Home-Based Component

Home based services permit highly individualized work with infant and family in their own setting. The ongoing relationship between staff and family developed in the home frequently is the key factor in the efficacy of the early intervention program. Home services are vital for young, medically vulnerable, chronically ill or easily overstimulated infants. They may also be essential for families who are not able to participate in center programs. To be most effective:

1) Home visits should be consistent, with a frequency based on family needs. Most programs find one visit per child per week most satisfactory.

2) The organization and goals of the home visit should include:

a. observation of infant behavior and developmental progress;

b. modeling and demonstration of developmentally appropriate activities for the infant which involves parents, siblings or other primary caregivers;

c. interactions with parents, siblings and other primary caregivers which positively reinforce their own developmental skills and activities with the baby;

b. discussion of parental concerns related to the infant and family, joint problem solving, and support for the parent in coping with the baby's special needs.

3) A primary and consistent home visitor (usually the primary intervenor) for the program should work with each family, so that an ongoing relationship can be formed . The home visitor can coordinate joint or individual home visits by other team members as needed.

4) Written or other guides should be left with the parent(s) in carrying out developmental activities between home visits. Parents should be encouraged to consult with the home visitor between home visits as needed.

5) The home program should make use both of play materials found in the home and toys and educational materials from the program's toy lending library.

6) The program budget should permit sufficient staff time and travel reimbursement for home visits.

B. Center-Based Components

Center based program components involve bringing the child, with or without parent, to a central facility. The center may be in school, medical, church or other facilities. Accreditation/licensing standards for facilities and staff unique to infant programs need to be developed and applied across agencies statewide.

Important components of center based programs include:

1. Adequate physical facility for center activities which includes,

   a. safe, adequate and appropriate indoor and outdoor activity space, organized and equipped for an infant population, and with adequate storage space.

   b. small rooms or partitions to permit quiet individual work with each infant

   c. availability of kitchen and bathroom facilities

   d. observation arrangements which may include a one way mirror and/or plans for incorporating visitors into group activities

   e. office space for staff which allows for privacy in respect for client confidentiality

   f. discussion and meeting space for parents and staff

   g. a lending library of toys and books for families

2. Transportation is advisable either by bussing, car pools, volunteer drivers or by some other way that makes the program accessible to all families, including those without cars, or access to public transportation.

3. Parent participation should be encouraged on a regular basis. Through regular particapation parents can: receive assistance in working with their own child, learn about other children, talk with other parents, interact with staff, and offer information about the child.

4. Opportunities for respite for the parent. A center program can offer the parent needed respite from constant care of an infant with special needs. Depending on the needs of the infant and parent, and resources of the program, respite may be offered for the whole duration of the program or for brief periods during the program.

5. Adequate adult: infant ratio. Depending on the developmental age and needs of the infant this will range from one infant per adult to no more than four-five infant per adult. Adults who make up this ratio can include staff, parents, consultants, paraprofessionals and volunteers, but there must be adequate planning, training and supervision by staff. Each infant should have opportunities for individual developmental activities with staff.

6. Opportunities for socialization and exploration by participating infants should be included as well as structured group and individual activities.

7. Immediate access to and/or staff training in emergency first aid procedures is needed.

C. Flexible Delivery of Services

Flexible and immediate services are essential to the preventive success of early intervention with infants with special needs and their families. Funding mechanisms across state agencies must permit such flexibility. Currently these mechanisms represent a primary deterrent to effective early intervention services.

1) Rigid eligibility criteria are inappropriate for the infant population. Funding for services must not be tied to rigid definitions of extent or type of handicap. Diagnostic procedures may require considerable time, and the extent and nature of handicapping conditions may not be clear for several years. Infants with identified or suspected developmental problems should be admitted for services immediately, even if on a provisional basis. Statewide eligibility criteria need to admit all disabled/handicapped infants. Statewide eligibility criteria need to be developed to enable appropriate preventive intervention services for medically and environmentally high risk infants.

2) Services must be flexible to meet the needs of the infants. Funding models must permit individualized services. The days, hours and types of services should be determined by the age and readiness of the infant. Long bus rides and long separations from the family generally are not appropriate. When service components are designed to meet respite and child care needs of working parents, programs must be designed to meet the infant's need for rest, exploration, and consistent caregiving. Infant needs also will change as the child gets older.

3) Services must be flexible to meet the needs of parents. Funding models should support early intervention services for the parent as well as the child. The types of services provided, and the times at which those services are provided should be determined, in part, by the needs of the family. The commitment to involve parents (particularly working parents) and family members may require some flexibility in hours, and some evening and weekend service components.

4) Expectations of parent involvement must be flexible. Parents vary widely in the ways in which they can benefit most from participation in an infant development program. While all parents should be involved, they may need to be involved in different ways at different times.

5) Services must be flexible to meet crisis and family events which are not uncommon to infants with special needs and their families. Funding models must permit programs to vary their services to families when needed to accomodate such events as:

- a. hospitalization of the infant
- b. personal, marital and other family crises
- c. respite care, temporary or permanent out-of-home care
- d. death of the infant, and the need for continued support to the family
- e. family needs for a temporary reduction in outside agency involvement
- f. birth of additional children
- g. parent needs to return to work

6) Different service models are needed, which correspond to identified infant, family and community needs. Funding models must support the availability of different service models. Infant development programs are most effective if they remain small (10-50 families) and responsive. No single program can provide all services to meet all infant and family needs. Instead different models which provide different types of services need to be encouraged and supported. No single model should be established as the only service for infants with special needs and their families.

III. Parent Involvement Component

While research has shown that parents must be active participants in order for an early intervention program to be most effective, parents may be active in many ways. Parents should be encouraged but not forced to participate in as many ways as they feel comfortable:

1) home-based developmental activities with the infant
2) center-based developmental activities with the infant
3) center based developmental activities with other children
4) individual and group counseling
5) informal parent support groups
6) parent education programs
7) social affairs with staff and parents such as picnics and potluck suppers
8) participation in infant assessment, program planning and evaluation
9) joint participation with other primary care providers, including other parent, grandparents, child care providers
10) membership on program's board of directors or advisory committee
11) community education and fundraising groups
12) making toys and equipment for the program
13) participating in advocacy efforts for services to children with special needs

IV. Record Keeping and Evaluation Components

While staff paperwork requirements should be kept to a minimum to allow the greatest use of staff time for service delivery, adequate record keeping and evaluation procedures are important to the quality of the program:

1) Records of infant assessments, services and progress should be maintained and shared (with signed consent by the parent) with physicians, preschool programs and other agencies providing services to the infant.

2) Confidentiality of participating infants and families must be protected. No records should be shared without the written consent of the parent.

3) Ongoing evaluation of the effectiveness of program services should be achieved at least by reviewing infant assessments, IPP's and longitudinal follow-up, as well as by reviewing indicators (both formal and informal indicators) of parental satisfaction and participation in program services.

V. Community Outreach, Supplementary Services and Placement Components

Community involvement by the infant development program is essential in order to: educate professionals and parents about the need for early identification of infants with special needs; obtain needed services for participating families; and assist appropriate placements of program graduates in preschool programs and other services.

1) The infant program must make efforts to educate both the professional and public community about the special needs of these infants and the resources available. This can be done through brochures, media coverage and other techniques.

2) The infant program should keep physicians and other agencies serving the infant informed about the progress and services to the infant with special developmental needs. With the written consent of the parent, copies of infant assessments, program plans and other records can be sent on a routine basis.

3) The infant program should be well informed about supplemental community resources for infants and families, and should assist participating families in contacting and making use of these resources. Such services may include primary health care, financial and housing assistance, mental health and child care resources, and so forth.

4) The infant program should assist the families of infants leaving the program in identifying and obtaining appropriate placement programs and services for themselves and the infant with special needs. For children leaving an infant program at age three, a critical point occurs in placement in special education, nursery school or other programs. The infant program ususally knows infant and family needs and can assist both families and potential placement agencies with recommendations, records, and transitional program suggestions.

RECOMMENDATIONS

1. A comprehensive coordinated state plan must be developed which establishes a local planning process for families with special needs infants birth to 3 years.

2. Appropriate infant development services for any child with special developmental needs must be made available in all areas of California.

3. Infant development programs need a stable and sufficient fiscal support base to sustain adequate staff and program quality.

4. Coordination of service delivery systems is needed to eliminate gaps in service and delays in entering service systems initially.

5. Quality standards need to be emphasized across all agencies providing services to infants.

6. A variety of program models need to be available to meet the needs of individual families.

7. Funding must permit services to infant and family, not just the infant.

8. Referral and eligibility processes need to be streamlined to minimize the delay in services.

9. Quality standards for staff composition and competencies should be developed.

10. State and local planning of services for infants with special needs must involve service providers and parents.

PREPARED STATEMENT OF MARGARET BURLEY, EXECUTIVE DIRECTOR, OHIO COALITION FOR THE EDUCATION OF HANDICAPPED CHILDREN, WORTHINGTON, OH

Mr. Chairman, Members of the Committee: My name is Margaret Burley. I am offering this testimony in my capacity as Executive Director of Ohio Coalition for the Education of Handicapped Children, MR/DD Legislative Coalition and for the Board of Directors of National Parent CHAIN. My testimony will address several topics dealing with the effects a handicapped child has on the family. In addition, I would like to discuss how public policies of dealing with individuals with handicaps are designed in ways which only aggrevate the pressures put on the individuals' family. Finally, I will examine some of the newer policy and program directions which, if followed through upon, could relieve a great deal of the pressure now weighing on hundreds of thousands of citizens nationwide.

My duties with the Ohio Coalition bring me into daily contact with parents and families who have a handicapped family member. This permits me to see a great many situations. Although all have their own unique elements, there is usually one problem they share in common. That is handling the pressures put on the entire family.

The pressures of raising a child with disabilities in our society are a tremendously frightening thing. A family can either emerge stronger than ever or as happens, all too often, it can end up tearing that family apart. The more you try to be a part of that child's life, the greater the stress that must be dealt with. Rarely does that stress hit a higher peak thru when the family must make a choice between institutionalizing their loved one and keeping them either at home or in the local community.

Since the early 19th century, our society has placed a heavy emphasis on institutionalizing the physically and mentally disabled. This was a radical departure with the more natural approach taken by the colonists. In Colonial times, the institution was yet to be discovered. Those with mental and/or physical disabilities lived in and were cared for by the community. This was true for orphans, the poor and criminals as well. The emphasis was on assisting the individual within the confines and abilities of the local community.

Institutions, for criminals, the poor, orphans and imbeciles sprung up quickly about the turn of the century. By the end of the 19th century they had become the method of first resort in dealing with these four groups. They became the source of great pride. Monuments to American ingenuity and efficiency.

To the families of persons with serious disabilities, especially at the time predating the establishment of community programs, the advent of the institution was a mixed blessing. On one hand it meant freedom from the personal and economic struggles that seemed so hopeless at times. On the other hand, you had to give up your child to the state.

In 1962, when my family and I faced our decision, things were not that much different then during the turn of the century. When the doctors told us our son Tom would be blind, deaf and brain damaged, probably his whole life, we were devastated. Initially we felt a sense of loss. The doctors recommended that both for the families sake as well as Tom's he be placed in an institution to live out his life. They felt it would spare us tremendous heartache as well as financial troubles if we gave up our son.

Looking back, I do not know how we ever decided to try to raise Tom ourselves. The odds were certainly stacked against it. The arguments in favor of institutionalization were very compelling. Our son would be cared for and we could resume living a normal life. We could be a normal family as our other three children had no disabilities. We would not have a face the long hours of attending to Tom's personal needs. We would not be faced with a choice of staying home or exposing ourselves to the rude stares of the community. Our sons and daughter would have had our equal attention rather than having a brother who was the focus of attention 24 hours a day. On the other hand, we would have to give up a son and the children, a brother.

At that time there were few alternatives to either the family home or the institution. Either the family kept the child home and assumed full responsibility for their habilitation and care or they relinquished the family member to the state run institutions.

Prior to the creation of the Medicaid program which was part of the Social Security Act of 1965, the states were presumed to have total responsibility for their respective developmentally disabled citizens. Quality and concern fluctuated from state to state. The Social Security Act and, in particular, the Medicaid program offered the states money for their developmentally disabled citizens in exchange for some uniformity and quality assurances. Chapter 42 of the United States Code sets out eligibility criterion which, if met by the state, can net the state about a 50% match money from the federal government.

Unfortunately for the family, most of this money is targeted for institutional care. Two of every three dollars goes for hospitals, skilled nursing facilities and Intermediate Care facilities. In 1985 it is estimated that of the total medicaid budget of $40.762 billion, 25% ($10.325 billion) will go for hospital care, 13% ($5.389 billion) for skilled care facilities and 29% ($11.975 billion) for intermediate care facilities. The priority is still given to the funding of institutions and public policy usually follows the funding priorities.

Families have been able to utilize the Education for All Handicapped Children Act of 1975, Public Law 94-142, which requires greater intervention by the public schools. The theory and philosophy of Public Law 94-142 are irreproachable. Unfortunately, the burden of actually enforcing compliance falls on the parents. Often at great financial and emotional cost.

More help may be on the way for families. This session, the Community and Family Living Amendments, S. 873 has been introduced in the U.S. Senate. The thrust of this legislation is for the federal government to shift its Medicaid subsidies from institutions to community and home based programs. As I stated earlier, currently a person must usually be in some form of institution or facility to benefit substantially from Medicaid. Most community or home based programs are funded through state or local dollars. Over a 15 year period, S. 873 would shift Medicaid funding exclusively to community or home based programs and require the states to be solely responsible for funding institutions.

Other incentives are appearing on the state level. Two years ago, Ohio started a program called Family Resources. It provides reimbursement for families who have a qualifying family member for whom they must purchase adaptive equipment or special foods. The cost of family counseling and respite care can also be reimbursed under this program. Respite care permits the family to take a break or a little vacation from the rigors of raising a handicapped child while ensuring the child has all their specialized needs met. A day off every once in a while can do wonders for falling morale.

Programs like Family Resources or those proposed by S. 873 represent the future of this field. We need to move back toward what came so natural to us in the first place, assisting individuals within the local community. It is not only more humane or cost effective. It is what comes naturally.

We must stop forcing parents to break up their families when a child is born with developmental disabilities. We should encourage them to take as large a roll as possible in raising that child. We should supplement their income as an incentive to keep the child at home. We also must create readily available community based services to meet the child's needs.

We hear a lot in the media about being pro-family, yet, rarely do people examine administrative policies dealing with the disabled in that light. If they did, they would find most of the policies anti-family. For instance, a family who is trying to work and care for a severely disabled child gets no extra deduction on their Federal income tax. If that family tries to get aid from the state department of welfare they are told to get a divorce so the mother is eligible for A.D.C.

U.S. Department of Education, Office of the Assistant Secretary for Special Education and Rehabilitative Services,
Washington, DC, April 29, 1985.

Hon. Dan Coats,
Ranking Minority Member, U.S. House of Representatives, Select Committee on Children, Youth and Families, Washington, DC.

Dear Mr. Coats: Thank you for your letter requesting the Office of Special Education and Rehabilitation Services to submit written testimony for the record of the Hearing, "Families with Disabled Children: Issues for the Eighties."

I appreciate the opportunity to present OSERS' views on this important topic. Please feel free to contact me if you have further questions.

Sincerely,

Madeleine Will, *Assistant Secretary.*

Enclosures.

Families With Disabled Children: Issues for the Eighties

The Office of Special Education and Rehabilitative Services (OSERS) is pleased to have the opportunity to present testimony regarding the issues facing families with disabled children. OSERS' programs have played a strong leadership role in bringing the family into the process of education of handicapped children. Following are a number of issues which we feel are of critical importance in this decade.

FAMILY STRESS

The addition of any new person to a family requires a lot of adjusting on the part of other family members. The addition of a child with a disability requires major adjustments, even in the ways other family members interact with each other. Of course, there are compensations that come with a handicapped child—including a heightened awareness of what is really important, and the joy of victories of the human spirit. There also is the same love that comes with any child. But for almost all families, there are also economic, psychological, and social problems that create stress.

The direct economic costs of providing extra services are somewhat obvious: transportation, baby sitters, attendants, tutors, clothing, camps, vacations, almost anything one can think of costs more, or is needed more often. The indirect cost is that the rest of the family often has to make do with less time, as well as money. Parents have to work longer hours to earn needed additional income, or irregular hours to be able to attend meetings, conferences, medical appointments. Siblings may be pressed into service as surrogate parents, when they still need parents themselves.

The psychological pressures on the family may include initial grieving and guilt, and the pain that comes from having to watch helplessly as the disabled child is rejected by peers. Social pressures come from relatives, friends, neighbors, schoolmates, and the people in supermarkets, movie theaters, and playgrounds whose excessive sympathy, or discomfort, or hostility are equally offensive, and often more difficult to deal with than the disability that elicits it.

Given these pressures, it is not easy for a family to resist defining itself in terms of its handicapped child. But the need for the child as well as the family is to resist that kind of skewing, to maintain a balance, to recognize that though one member of the family may have more obvious requirements, all have needs that must be addressed. All of the children in a family need their own time with their parents and time to themselves. And parents need time with each other. Both children and parents may need counseling and respite from their obligations of caring for, or being cared for.

The primary issues to be considered are:

Respite Care
Parent Burnout
Family Counseling
Roles of Siblings
Values Clarification
Information for Planning
Negotiating Education/Medical and Related Systems

Many of OSERS programs have elements dealing with reducing family stress. This is a major issue especially in many of our early childhood education programs and in our parent training and information centers. Stress is often a result of inadequate information. We also support two projects specifically to provide better information services. These are the National Information Center on Handicapped Children and Youth and the Direction Service Center. This latter project is especially important in helping families negotiate the maze of service providers in a system of service delivery which is extremely fragmented and complex. In addition, our general philosophy of encouraging parents to become more directly involved in the education of their handicapped children should be a highly positive factor in reducing the effects of family stress.

SCHOOL-TO-WORK TRANSITION

Youth with disabilities face an uncertain future when they leave the Nation's public schools. Qualification for employment is an implied promise of American education. However, between 50 and 80 percent of working age disabled adults are jobless.

The absence of meaningful employment opportunities has caused many individuals to seek out community services. Parents, professionals, and handicapped adults are quickly learning that appropriate community services are very scarce. Those community services that may be available often fail to provide meaningful employment training and segregate individuals from their non-disabled peers.

Congress recognized this situation and created the Secondary Education and Transitional Services for Handicapped Youth Program. The U.S. Department of Education, Office of Special Education and Rehabilitative Services has responded to this concern by establishing a priority for the improvement of transitional services for handicapped youth.

The Education of the Handicapped Act Amendments of 1983, P.L. 98-199, created the Secondary and Transitional Services for Handicapped Youth Program (Section 626). The purposes of this program is to: (1) strengthen and coordinate education, training, and related services to assist in the transitional process to post secondary, vocational training, competitive, or supported employment, continuing education, or adult services, and (2) stimulate the improvement and development of programs for secondary special education. Appropriations for Fiscal Year 1985 are in excess of 6 million dollars. Eligible applicants for funding include institutions of higher education, State and local school districts, public or private nonprofit agencies or organizations, and State Job Training Coordinating Councils and Private Industry Councils authorized under the Job Training Partnership Act.

Each unit within the Office of Special Education and Rehabilitative Services (Special Education Programs, National Institute for Handicapped Research, and Rehabilitation Services Administration) has given top priority to the development, expansion, and improvement of transitional services. Special Education Programs provides Federal leadership for improving the transition of handicapped youth from school to work and adult life by:

Communication and dissemination of Federal policy and information on the education of handicapped children and adults.

Administration of formula grants and discretionary programs authorized by Congress.

Encouragement and support of research and the development of knowledge and innovations for the education of handicapped children and adults.

Encouragement and support of the use, demonstration, and dissemination of models and practices.

Promotion and support of the training of educational, related services, and leadership personnel and parents.

Evaluation, monitoring and reporting on the implementation of Federal policy and programs and the effectiveness of efforts to educate handicapped children and youth.

Promotion of interaction and coordination among other Federal agencies, State agencies and the private sector including parent and professional organizations, private schools, and organizations of handicapped persons for the identification and review of policy, program planning and implementation issues.

LEAST RESTRICTIVE ENVIRONMENT

The concept of education in the least restrictive environment (LRE) is the cornerstone upon which Federal special education policy is built. Two principles regarding the placement of handicapped children and youth are established in P.L. 94-142. The first principle establishes that there is a requirement to place a child in an appropriate setting for learning. For some children that may be a regular classroom, for others it may be a special classroom setting which least restricts the child from entering the mainstream of educational development. Any departure from that practice requires a compelling justification. The second principle is that most handicapped children and youth must be educated with children who are not handicapped and addresses the degree of student integration. These are some of the issues of LRE for the 80's:

Assessment of current service delivery systems;

Development of appropriate service delivery systems;

Implementation of appropriate service delivery systems;

Institution of effective mechanisms for evaluation of services;

Provisions of training for general education teachers by qualified special educators;

Provision of fully trained and certified special education personnel.

PARENTS AS MEMBERS OF THE EDUCATIONAL TEAM

The goal of the educational team which develops the individualized education program (IEP) is to evaluate and determine the most appropriate environment for a child who is handicapped. Hopefully, all children who are handicapped will be placed in an environment allowing them to develop to their fullest potential. In order for this ideal to be reached, it is crucial that the people who know the child best be working members of this team. Professionals and parents both have significant roles to play in this effort.

Being part of the educational team may present a problem for parents who are often not as trained to deal with such meetings as professionals are. The major problems parents have are these:

(1) Parents are often unaware of their rights and the whole assessment process. Parent advocacy groups have helped to eliminate this problem to some degree, but many of the parents who are not middle class, or of the cultural majority, still do not receive adequate information.

(2) Parents are sometimes unwilling to exercise their rights even when known. This may occur due to many factors, but some of the most common ones include: a) a fear of the total system, b) feeling overwhelmed by the educational team of professionals, c) not understanding the vocabulary used, and d) feeling they don't know enough to contribute anything of value. Professionals must be aware of these factors and work to encourage parents to understand that they do make a difference and have crucial information that should be included in the decision making process.

(3) Parents are sometimes seen as uninformed by professionals, and, as a result, unqualified to take part in decision making. On the other hand, parents who are very knowledgeable are sometimes seen as a threat by professionals. These negative attitudes need to be dealt with if children are to be best served.

(4) Parents are sometimes unable or unwilling to see the total picture of their child. They may choose to see only "good" points or they may expect too much, or may be over protective, and expect too little. Most parents are protective of their children but this emotionally charged issue needs to be dealt with or it can hinder acceptance of an appropriate placement.

Persons concerned with the child's best interest need to become aware of these problems and to sensitively tackle each one. All of these problems can and should be dealt with because effective involvement of parents and educational professionals is necessary if each child with a handicap is to be helped to reach his/her fullest potential.

EARLY INTERVENTION

Part B of the Education of the Handicapped Act (EHA-B) and the implementing Federal regulations (34 CFR Part 300) require the provision of special education and related services to children and youth from age three through twenty-one. Although other Federal programs (Sec. Part D of the EHA; 34 CFR 318) do include some focus on infant intervention, the lack of requirements for State educational agencies (SEAs) to report handicapped infants deters Federal monitoring. Appropriate amendments to the EHA-B clearly would enhance more effective Federal monitoring of desirable early intervention.

Some of the more dramatic examples of progress and discovery in medicine and in education have taken place in the treatment and stimulation of infants and preschool aged children who have disabilities. Progress in serving these children has increased more in the last decade than in ten generations before it. Yet services are still not available to all handicapped children, ranging in age from birth to five, nor is the spectrum of services available to those very young handicapped children who need extensive, focused, comprehensive treatment and education to give them a viable start in life.

The solutions to providing quality services to infant and preschool handicapped children are known, but far too often they are not acted upon. To facilitate the type of services needed by preschool disabled children, members of several traditional disciplines, e.g., medicine, education, recreation, child care, etc., must work together, blending their specialties to the task of nurturing and educating a handicapped child. Although theoretically possible, the service models that actually promote true interdisciplinary intervention to a handicapped infant or child are rare.

* * * recreation, child care, etc., must work together, blending their specialties to the task of nurturing and educating a handicapped child. Although theoretically possible, the service models that actually promote true interdisciplinary intervention to a handicapped infant or child are rare.

Whether because of traditional disciplinary rivalries or through lack of transdisciplinary education, this hinderance to comprehensive interdisciplinary treatment/education of preschool handicapped children is an obstacle that can best be removed by reform and innovation in the academic preparation of these professionals. OSERS' Division of Personnel Preparation (DPP) funds the start of such programs.

The other obstacle to the needed quantity of such services for young handicapped children is the lack of facilitating legislation within states. Interdisciplinary professionals need to be paid for working with children. Buildings and facilities must be provided. Quality standards must protect the client from poorly trained or administered programs or personnel. Only a few states now encourage a full complement of intervention personnel and facilities. Federal grants are assisting States in planning for the initiation of legislation, but many States are resistant. Again, the universities must research the problems and train administrators in their solutions before acceptance will be fully obtained.

RECREATION

Families of handicapped children need to be systematically appraised of the myriad benefits to be derived from recreation programs. Such programs are an important tool for enhancing the educational development of handicapped children and youth.

To assure the widespread availability of such programs to all handicapped children and their families, written policies and guidelines for implementation need to be established. Uniform practices, certification, and licensing need to be sanctioned. Appropriate personnel preparation must accompany the clearly defined roles and functions of recreation specialists and ultimately affect the effectiveness of recreation programs. And finally, opportunities need to be provided for the integration of handicapped children and youth into programs with non-handicapped peers.

QUALITY FOR THE 80S

The improvement of educational services for handicapped children and youth in this country ultimately depends on improving the preparation and certification of school personnel so that those who enter and remain in the teaching profession are competent. To achieve this, a number of specific areas need to be strengthened:

Temporary or Emergency Certification
National Accreditation
State Program Approval
State Certification
Technologies
Rural Service Delivery
Linkages and Collaborative Arrangement
Recruitment, Admission, and Retention
Faculty/Staff
The Preservice Program (Including Curriculum & Competencies & Practical Experience)
Research
Evaluation

CONCLUSION

In conclusion, OSERS has identified a number of issues of importance in the eighties: the transition from school-to-work, parent involvement in the decision making process related to the disabled child, family stress, the least restrictive environment, recreation issues, and the education of all health professionals and related personnel working with disabled new borns. Inroads in these crucial areas will impact significantly on the quality of education, and ultimately on the quality of life, for all disabled individuals.

U.S. House of Representatives,
Select Committee on Children, Youth, and Families,
Washington, DC, May 17, 1985.

Ms. Beverly Bertaina,
Sebastopol, CA

Dear Ms. Bertaina: This is to express my personal appreciation for your appearance before the Select Committee on Children, Youth, and Families at the hearing held in Anaheim, California, "Families with Disabled Children: Issues for the 80's." Your participation contributed greatly toward making the hearing a success.

The Committee is now in the process of preparing the transcript of the hearing for publication. It would be helpful if you would go over the enclosed copy of your testimony to make sure it is accurate, and return it to us within three days with any necessary corrections.

In addition, Congressman Lehman has requested that you answer the following questions for the record:

1. What can you tell the Committee about the extent and quality of hospice care and respite care for families with disabled children?
2. Do you have any information on how these types of care differ from state to state?
3. Are you familiar with any experiences that other countries have had with hospice and respite care from which we can learn?
4. Has any information grown out of the hospice movement for the terminally ill elderly that we can use to encourage better programming for disabled children and their families?

Let me again express my thanks, and that of the other members of the Select Committee, for your testimony.

George Miller, *Chairman.*

Enclosure.

To: House Sub-Committee on Children Youth & Families.
From: Beverly Bertaina, Sebastopol, CA.
Date: May 20, 1985.

Re: Respite Care for Disabled Children.

Respite care varies a great deal in the counties within the state of California. There is no respite in many areas, very little in some areas & an inadequate amount in a few areas.

But respite (a break from the care of a disabled child) is not the only need of families. We need part-time attendant care, but funding is available only for adult disabled people. Attendant care provides help with our disabled child while we're home, help to do some of the lifting, transferring, bathing, feeding, diapering, therapy, etc.

I would like to caution Congressman Lehman in his interest in hospice programs & programs that use disruptive students to peer tutor disabled students. The jextaposition of deviancy has often been used to get 2 deviant groups (such as problem kids or the terminally ill & the disabled) out of the way and kill 2 birds with one stone. The problem is that this process results in lowering the status of both groups (who need a raised status in the eyes of the world), in lower standards within the program, and in isolating both groups from the mainstream (where they need to be). Both groups of kids often end up learning more deviant behavior from each other, not less.

I feel strongly that my disabled child must be afforded the same quality & protections as most parents demand for their non-disabled children. If a peer tutor program is established with disruptive students then 90% must work with non-disabled kids & 10% with the disabled. Only in that way can we insure that the program will have sufficient quality & protections.

It is also important to remember that, although our disabled children often have medical needs, they are not ill. Their medical needs are usually not their most important needs; their educational, developmental, social, communications needs are central. Providing programs based on the medical model can be extremely unbalanced & harmful.

House of Representatives,
Select Committee on Children, Youth, and Families,
Washington, DC, May 17, 1985.

Ms. Florence M. Poyadue, R.N., M.A.
Executive Director, Parents Helping Parents,
San Jose, CA.

Dear Ms. Poyadue: This is to express my personal appreciation for your appearance before the Select Committee on Children, Youth, and Families at the hearing held in Anaheim, California, "Families with Disabled Children: Issues for the 80's." Your participation contributed greatly toward making the hearing a success.

The Committee is now in the process of preparing the transcript of the hearing for publication. It would be helpful if you would go over the enclosed copy of your testimony to make sure it is accurate, and return it to us within three days with any necessary corrections.

In addition, Congressman Lehman has requested that you answer the following questions for the record:

Are you aware of any hospice programs for children and their families in the Washington, D.C. area, South Florida, or anywhere else there might be model efforts?

Let me again express my thanks, and that of the other members of the Select Committee for your testimony.

Sincerely,

GEORGE MILLER, *Chairman.*

Enclosure.

PARENTS HELPING PARENTS INC.,
San Jose, CA, May 20, 1985.

GEORGE MILLER,
Chairman, Select Committee on Children, Youth, and Families, U.S. House of Representatives, 385 House Office Building Annex 2, Washington, DC.

DEAR SIR: I have enclosed my corrected copy of the testimony given before the Select Committee on Children, Youth, and Families in Anaheim, California.

In answer to Congressman Lehman's request: Are you aware of any hospice programs for children and their families in the Washington, D.C. Area, South Florida, or anywhere else there might be model efforts?

I talked with the Director of Hospice of the Valley of San Jose, California. She states that their hospice, and most hospices are open to children. She also hastened to add that in six years of operation, they have only served three clients under 18 years of age. Their youngest was 17 years old. They have no age limits though. She feels that they have not seen use of their services for children for possibly two main reasons:

No. 1. Parents cannot bring themselves to acceptance of their child's death, so they cannot let go. Using a hospice would indicate that they are doing just that, so they shy away from the concept of hospices.

No. 2. Support for parents is available in most children's hospitals on the oncology units.

There is also support for parents through an organization called Candlelighters; their national address is Suite 1011, 2025 Eye St. NW, Wash., DC 20006. Ronald McDonald Houses are sometimes attached to children's oncology units.

I talked with a Dr. Silvo Margolis in San Francisco (456 Columbus Ave. S.F., CA. 94133—Ph: 415-989—7550) who operates a Pediatric House Call Agency. It is a type of hospice service as he explains it. He considers it a model for child care in the home. He will be in Bethesda at the Holiday Inn on 8120 Wisconsin Ave. July 29-August 2. Someone might want to get in touch and get more information about his concepts.

Also, there is a Dr. John Golinski at Childrens Hosp. of Oakland (415-428-3000). He is the Director of Psychological Services and may well be able to supply further information on this topic for Congressman Lehman.

Respectfully,

F.M. POYADUE, RN MA

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES,
Washington, DC, May 17, 1985.

ANN P. TURNBULL, Ed.D.
Lawrence, KS

DEAR DR. TURNBULL: This is to express my personal appreciation for your appearance before the Select Committee on Children, Youth, and Families at the hearing held in the Anaheim, California, "Families with Disabled Children: Issues for the 80's." Your participation contributed greatly toward making the hearing a success.

The Committee is now in the process of preparing the transcript of the hearing for publication. It would be helpful if you would go over the enclosed copy of your testimony to make sure it is accurate, and return it to use within three days with any necessary corrections.

In addition, Congressman Lehman has requested that you answer the following questions for the record:

1. What can you tell the Committee about the extent and quality of hospice care and respite care for families with disabled children?
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3. Are you familiar with any experiences that other countries have had with hospice and respite care from which we can learn?

4. Has any information grown out of the hospice movement for the terminally ill elderly that we can use to encourage better programming for disabled children and their families?

Let me again express my thanks, and that of the other members of the Select Committee, for your testimony.

Sincerely,

George Miller, *Chairman.*

Enclosure.

The University of Kansas,
Bureau of Child Research,
Lawrence, KS, May 24, 1985.

Representative Miller,
Select Committee on Children, Youth, and Families, H2-385, Annex 2, Washington, DC.

Dear Representative Miller: Enclosed is the revised transcript of my testimony of April 19.

I am not qualified to answer questions about hospice, but I refer your staff to "Mental Retardation," Vol. 22, No. 4, August 1984 for a symposium about hospice.

It was a pleasure to have worked with your committee and you, and my husband and I stand ready to help you at any time.

Very truly yours,

Ann P. Turnbull,
Acting Associate Director.